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**Friendship and intimate relationships in people
on the autism spectrum**

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Submitted in partial fulfilment of the requirements for the
Doctorate in Clinical Psychology

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Declaration

This research was carried out under the supervision of Mr Jacky Knibbs, Dr David Sanders and Dr Gavin Farrell. Apart from contributions to the initial ideas and comments on written drafts by these people, this thesis is all my own work. The thesis has not been submitted for a degree at any other university. None of the papers have yet been submitted for publication. The literature review and empirical paper have been prepared for submission to *Autism* and the reflective paper has been prepared for submission to *Good Autism Practice*. All names and other means of identification have been removed to ensure participant anonymity,

Summary

Chapter one considers the literature on sexuality and long-term relationships in people with autism spectrum disorders (ASD). The research has many methodological flaws, however it is clear that sexuality and long-term relationships are important to people with ASD. Their difficulties with social interactions may impact on the development of sexuality, and this can lead to inappropriate sexual behaviours and difficulty initiating relationships. It is suggested that further research would add to our understanding of sexuality and relationships for people with ASD. It is recommended that services should focus on supporting the development of appropriate sexual behaviours, and improving the social support networks of individuals in relationships.

Chapter two explores the experiences of friendship in six adults with Asperger syndrome or high functioning autism (AS/HFA). Interpretative Phenomenological Analysis is used to identify themes from the interviews. The super-ordinate themes are: defining friendship, maintaining friendships, difference, increasing self-awareness and maturity, and future desires. The participants particularly highlight the importance of friendship. The results are discussed in relation to existing research, and limitations of the study are considered. It is suggested that interventions by statutory and voluntary organisations should focus on early diagnosis of AS/HFA and the facilitation of friendships for adults.

Chapter three provides a reflective account of conducting qualitative research with people on the autism spectrum. Reasons for the limited use of qualitative research with this group are considered, and challenges to the research process are discussed. It is argued that people on the autism spectrum have valuable contributions to add to our understanding of friendship, due to their focus on detail. The idea that autism should be seen as a difference rather than a disability is briefly discussed with reference to the empirical paper.

CHAPTER ONE

What is known about sexuality and long-term relationships in people on the autism spectrum?

Word count: (excluding table, references and footnotes).

1.1. Abstract

Sexuality and long-term relationships have been identified as of considerable interest and importance to people with autism spectrum disorders, in autobiographical accounts such as Stanford (2002). Much of the outcomes research suggests that sexual experiences and marriage occur infrequently in this population (e.g. Howlin et al., 2004). The literature on sexuality and relationships in people with autism is systematically reviewed, and findings are presented on the following topics: development of sexuality in children and adolescents, knowledge and understanding of sexuality, sexual activity in adults, sexual issues and problematic sexual behaviour, and long-term relationships. The research is critically evaluated, and the review concludes that the difficulties individuals encounter with social interaction can negatively impact on the development of sexuality. It is recommended that interventions should focus on supporting the appropriate expression of these desires, and strengthening existing social networks. Ideas for future research are presented.

1.2. Introduction

Current ICD-10 diagnostic criteria (WHO, 1992) include a range of diagnoses under the group term of Pervasive Developmental Disorders, including Childhood Autism and Asperger's Syndrome. In general, the conditions are characterised by abnormalities in reciprocal social interactions and patterns of communication, and by a stereotyped, repetitive repertoire of interests and activities. There may also be a degree of cognitive impairment. The term 'autism spectrum disorders' (ASD) is widely used in the literature and will therefore be used throughout this review.¹

Given the documented social difficulties experienced by people with ASD, it could be predicted that intimate relationships may be difficult. Several recent qualitative studies have explored the nature of social challenges from the perspective of individuals with ASD, and demonstrate that individuals long for intimacy and social connectedness (Müller et al. 2008²; Sperry and Mesibov, 2005). However, participation in social activities and peer relationships is often limited (e.g., Orsmund et al., 2004). The complexities of interpersonal relationships can be extremely difficult to decode and make sense of (Hénault, 2005).

A number of studies have focused on the adult outcomes of people with ASD, and have demonstrated low levels of sexual relationships and marriage (e.g. Howlin et al., 2004). A review by Seltzer et al. (2004) concluded that few adults with autism live

¹ See Appendix F for submission criteria for the journal 'Autism', which recommends the use of 'people with autism' or 'people with ASD'. The latter has been chosen to reflect the spectrum of difficulties encompassed within this review. A wide variety of terminology is used by the articles within the literature review, and this is reported as per each paper.

² 'et al.' is used throughout the review where there are three or more authors, in accordance with SAGE Harvard referencing style, requested by the journal Autism. See reference list for full list of authors.

independently, develop a large network of friends or marry; many remain dependent on their families or professionals for assistance with tasks of daily living. However, Seltzer et al. (2004) highlight the subgroup of 15-25% of adults typically with higher IQs (high functioning autism – HFA) who show more favourable outcomes, living independently and having relationships. Engström et al. (2003) reported considerable independence in a group of adults with HFA, however few reported long-term relationships.

Despite the relative paucity of empirical research, there is an increasing body of autobiographical accounts of the experiences of people with ASD (particularly HFA) and their partners in relationships (e.g. Slater-Walker and Slater-Walker, 2002; Hendrickx and Newton, 2007; Stanford, 2002). These accounts demonstrate the motivations of people with ASD to have long-term intimate relationships, and the challenges individuals and their partners experience as a result of the ASD. These descriptions are supported by various clinical accounts, for example, Attwood (2006).

1.2.1. Rationale for the current review

The nature of the social difficulties associated with ASD would suggest relationships may be difficult to initiate and maintain. Autobiographical accounts support the idea that people with ASD do have successful relationships, despite these difficulties.

There are no known review papers on this topic, therefore the focus of this literature review is to evaluate critically the existing research on sexuality and long-term relationships in people with ASD, to identify clinical implications of this work and areas for future research.

1.2.2. Search strategies

Literature searching was carried out between September 2010 and March 2011. The databases PsychINFO, Web of Science and EMBASE were used to search for relevant articles from peer-reviewed journals. Search terms included 'autis*' (denoting anything beginning with autis) OR 'Asperger*' AND 'sexuality' OR 'long term relationship'. Further cited reference searches were carried out using Web of Science using recent relevant articles. The contents of the journal Autism were also searched using the above terms.

Articles were considered for inclusion if they were post 1985, English language, and involving primary research with individuals with any autism spectrum condition, or with their parents or carers. Abstracts were read to determine relevance to the topic. Use of this criteria resulted in 14 studies being included in this review. Following examination of these papers, five general themes within the literature were identified: development of sexuality in childhood and adolescents, knowledge and understanding of sexuality, sexual activity in adults, sexual issues and problematic behaviour, and long-term relationships. A number of the articles contributed to several themes.

1.3. Table of studies

Table 1 summarises the studies included in the literature review.

Study	Participants	Number of participants	Ages	Study methods	Major findings
Hellemans et al. (2007).	Professional caregivers of male adolescents with Autistic Disorder, Asperger Syndrome or PDD-NOS (all high functioning).	24 adolescents.	Range: 15-21.	Interview about Sexuality in Autism (ISA - developed for study).	Normal age-appropriate sexual behaviour was present in many subjects. Sexual development was considered problematic in 1/3 of the group and intervention was justified.
Hellemans et al. (2010).	35 group home caregivers of males with Autistic Disorder (AD) living in institutions, and persons with borderline/mild mental retardation (MR) without AD.	20 with AD, 19 with MR without AD.	Range: 15-21.	The Interview about Sexuality in Autism-Revised (ISA-R).	Individuals with AD were reported to express sexual interests and display a variety of sexual behaviours. The sexual development level reached by individuals with AD was limited. Some individuals with AD had stereotyped sexual interests and sensory fascinations.
Kalyva (2010).	Teachers of children with low functioning autism (LFA) or high functioning autism (HFA).	Children: 56 with LFA, 20 with HFA.	Range: 7-14.	Sexual Behavior Scale (SBS).	Children with LFA were reported to exhibit more problematic behaviours than those with HFA. Children with HFA had a better understanding of sexuality issues. However, teachers expressed more concerns for the children with HFA.
Konstantareas & Lunskey (1997).	Participants with AD and participants with developmental delay (DD).	16 with AD, 15 with DD.	Range: 16-46.	Socio-Sexual Knowledge, Experience, Attitudes, and Interests test (SSKEAI), Developmental Profile II.	Awareness of sexual terminology was correlated with level of cognitive functioning. Women reported fewer sexual experiences than men. There was a negative correlation between knowledge and endorsement of sexual activities.

Study	Participants	Number of participants	Ages	Study methods	Major findings
Lunsky and Konstantareas (1998).	Participants with an AD or MR. Non-matched undergraduates and matched community control groups.	15 with AD, 16 with MR. Control groups: 25 and 28.	Range: 16-46.	Socio-sexual knowledge and attitudes test (SSKAT).	The AD and MR groups were significantly less accepting of 12/20 situations presented. Those with AD were slightly more accepting.
Mehzabin & Stokes (2011).	Participants with HFA or Asperger Syndrome (AS), typically developing (TD) control group.	21 with HFA/AS, 39 TD.	Mean age of HFA/AS = 23, Mean age of TD = 24.	Adapted version of the Sexual Behaviour Scale (SBS).	Individuals with HFA reported engaging in fewer social and sexual behaviours than TD individuals. Sex education levels were lower in the HFA group. The HFA participants had a higher level of concern for their future.
Miyahara et al. (2008).	Mothers of sons with autism in Japan, categorised as severe or non-severe.	Children: 41 severe, 30 non-severe.	Range: 6 – 25.	Questionnaire survey of sexual development and behaviour, Moroi's marital quality scale.	No physiological differences were found according to severity of disability. The non-severe group began to show interest in the opposite sex much earlier than the severe group. 50% of the children masturbated.
Ousley & Mesibov (1991).	Adults with HFA, or MR without autism.	21 with HFA, 20 with MR.	Mean age of both groups= 27.	Sexuality vocabulary test, and multiple choice questionnaire assessing experiences and attitudes about sexuality and dating.	Males were more interested in dating and sexuality than females. Autistic participants had less experience with sexuality than mentally retarded subjects without autism. There was a significant correlation between sexual knowledge and IQ. Knowledge didn't correlate with either interest or experience.

Study	Participants	Number of participants	Ages	Study methods	Major findings
Pollman, et al. (2010).	Dutch newlywed couples (non-clinical sample).	195 couples.	Mean age of men = 33. Women = 30.	Autism Spectrum Quotient (AQ), Dyadic Adjustment Scale (DAS), Rosenberg self-esteem questionnaire, Experiences in Close Relationships Questionnaire, relationship-specific self-disclosure scale, responsiveness scale, Perceived Relationship Quality Components – intimacy subscale, partner-specific trust scale.	Men with more autistic traits reported less relationship satisfaction. Partner's autistic traits were not related to people's relationship satisfaction. Among male participants, responsiveness towards the partner, trust in the partner and intimacy mediated the link between autistic traits and relationship satisfaction.
Renty & Roeyers (2007).	Couples, married/cohabiting for at least 1 year, where the male had a formal diagnosis of ASD.	21 couples.	Range: 35-54.	Autism Spectrum Quotient (AQ), Social Provisions Scale – spouse (SPS-S) and family/friends (SPS-F), Inventory of Social Supportive Behaviors – spouse (ISSB-S) and family/friends (ISSB-F), Camberwell Assessment of Need (CAN), ways of coping questionnaire, Symptom Checklist-90 (SCL-90), and Dyadic Adjustment Scale (DAS).	Fewer autistic traits in men were related to higher levels of marital satisfaction in women. Social support from the informal network was related to individual and marital adaptation in men and women. Formal support from professionals and services was not related to individual or marital adaptation. Avoidance coping strategies were related to lower levels of individual adaptation.

Table 1. Papers included within the current literature review, listed alphabetically.

Study	Participants	Number of participants	Ages	Study methods	Major findings
Ruble & Dalrymple (1993).	Parents of children with autism.	100 children.	Range: 9-38.	Sexuality Awareness Survey (SAS).	The verbal level of the individual was associated with parents' belief about the relevance of sex relations and sex education. No relationship was found between the verbal level of the individual and display of inappropriate sexual behaviours.
Stokes & Kaur (2005).	Parents of children with HFA/AS, and parents of TD controls.	Children: 23 with HFA/AS, 51 TD.	Range: 10-15.	Sexual Behaviour Scale (SBS).	Individuals with HFA displayed poorer social behaviours, engaged in fewer behaviours related to privacy, had poorer knowledge regarding privacy issues, had less sex education, displayed more inappropriate sexual behaviours and parental concerns were greater.
Stokes, Newton & Kaur (2007).	Parents of adolescents/adults with ASD, and parents of TD controls.	Adolescents /adults: 25 with HFA/AS, 38 TD.	Range: 13-36.	Courting Behaviour Scale (CBS).	Social functioning was the only significant influence on level of romantic functioning. ASD individuals' reported level of romantic functioning was significantly lower than that of their typical peers. ASD participants sought to initiate fewer social and romantic relationships but across a wider variety of people. They could not discriminate between appropriate and inappropriate behaviours, or be discerning in their target.
Van Bourgondien et al. (1997).	Staff of residential homes/supervised apartments supporting adolescents/adults with ASD.	89 people with ASD.	Range: 16-59.	Demographic form, sexuality questionnaire, Aberrant Behavior Checklist (ABC).	The majority of individuals engaged in a range of sexual behaviours. Use of objects in masturbation was reported. Individuals who masturbated were more likely to engage in stereotypic behaviours. There was no relationship between irritability, agitation and aggressive behaviour, and masturbation or person-oriented sexual behaviour.

1.4. Literature Review

1.4.1. Development of sexuality in childhood and adolescence

Several studies consider the development of sexuality in people with ASD, looking at the emergence of sexual interest and behaviours in childhood and adolescence.

Some contrast these findings with sexual development in the general population.

Miyahara et al. (2008) analysed questionnaires from 71 mothers of children aged six years and over, diagnosed with ASD. Their results suggested that children with severe ASD first demonstrated an interest in the opposite sex significantly later than children with non-severe ASD. Children with more severe ASD were more likely by the age of 10 years old to have masturbated in public than the non-severe group. Fifty percent of the total sample were reported to masturbate, the proportion being significantly larger in the severe group, however this is dependent on the accuracy of the mother's reporting. It is also important to note that the youngest participant was six years old and the oldest was 25, therefore many children included in the study may not have reached sexual maturity. There was also no control group of typically developing children.

Stokes and Kaur (2005) recruited 23 parents of adolescents with HFA and 51 parents of typically developing (TD) children (all aged 10-15), and explored their views of their children's sexual knowledge and behaviour using the Sexual Behaviour Scale.

Individuals with HFA were reported to engage in less social behaviour than TD adolescents. They were less aware of privacy related rules, and had poorer knowledge regarding sexually related issues such as acceptable behaviour towards a

person of romantic interest. Participants with HFA were more likely to display inappropriate sexual behaviours including touching others inappropriately and masturbating in public. Social behaviour became more frequent with age in individuals with HFA, but less frequent in TD adolescents. The authors suggest this could reflect decreasing parental knowledge of the behaviours of TD adolescents with age, or increased educational demands. The analysis of developmental patterns revealed that at 15 years old, individuals with HFA displayed a level of sexual behaviour similar to a 10 year old TD adolescent. Smaller lags were evident for privacy behaviours and sex education. However, it is important to note the small sample sizes and difference between the groups – 23 with HFA versus 51 TD adolescents – which could make the groups difficult to compare accurately, and the results hard to generalise. In addition, the Sexual Behaviour Scale was developed specifically for the study and validity had not been tested, therefore it may not have accurately captured participants' experiences.³

Kalyva (2010) also used the Sexual Behaviour Scale to investigate the perspectives of teachers on the sexuality of 76 children at their school aged between seven and fourteen, categorised as either having low functioning autism (LFA) or HFA. Children with HFA were reported to exhibit more socially acceptable behaviours than those with LFA, and more privacy seeking behaviours. Children with HFA were also reported to have received more sex education than those with LFA, and to have a better understanding of sexuality issues. Children with LFA had a reported history of less appropriate sexual behaviours and decreased knowledge of typical sexual responses.

³ A modified version of this scale was used by Mehzabin and Stokes (2011); see section 1.4.2. Reliability was tested using Cronbach's alpha and was found to be high for some subscales, but poor for others.

Teachers expressed more concerns however for the children with HFA, which the author suggests may be due to the increased opportunities available for sexual encounters. Whilst the sample size was higher than many studies, this research was limited by only examining the sexual behaviour of children in a school environment, making the findings difficult to generalise. There was also no control group, so no indication of how children with ASD compare to typically developing children or those with a learning disability.

In a study by Hellemans et al. (2010), the caregivers of 20 male adolescents and young adults with a diagnosis of ASD and borderline/mild learning disability (LD) were interviewed using a revised version of the Interview about Sexuality in Autism⁴, along with the caregivers of 19 individuals matched on age and IQ with borderline/mild LD without ASD. Individuals with ASD were reported to show significantly more difficulties with external bodily changes during puberty, for example, the development of pubic hair. The authors suggest this could be due to difficulties adapting to change often associated with ASD. However, this conclusion was drawn from the answer to a single question ('Did X show difficulties related to the physical changes of the body during puberty, e.g. morning erections, breast development, menstruation?'), so little can be concluded about particular difficulties with sexual development associated with ASD.

1.4.2. Knowledge and understanding of sexuality

A number of studies have focused on knowledge and understanding of sexuality and related issues in people with ASD, in comparison to TD controls or those with LD.

⁴ Developed by Hellemans et al. (2007).

Ousley and Mesibov (1991) interviewed 21 adults with HFA and 20 adults with mild to moderate LD, using questionnaires assessing sexual vocabulary, experiences and attitudes about sexuality and dating. IQ was a good predictor of sexual knowledge in both groups, suggesting that understanding or participating in sexual activities is not an essential pre-requisite for defining sexual terms correctly. Knowledge did not correlate with sexual interest or experience; this does not support the concerns some parents and carers have about increasing their child's interest in sexuality if education is provided.

Ruble and Dalrymple (1993) developed and sent the Sexual Awareness Survey (SAS)⁵ to the parents of children and adults with ASD; they received 100 responses, reflecting 32 females and 68 males. Individuals with higher verbal skills were reportedly more likely to have knowledge and understanding about sexuality, and to be taught rules. Ninety percent of the sample reported that their child had been taught specific rules around private behaviours, including undressing and touching private parts, using methods such as reinforcing appropriate behaviour and modelling.

Hellemans et al. (2007) interviewed Flemish group home caregivers of 24 institutionalised male adolescents and young adults with HFA using the Interview about Sexuality in Autism, developed for the study. All but one resident were reported by the respondents to show an interest in sexuality. The theoretical knowledge of self-care and socio-sexual skills was rated as adequate, although

⁵ Developed using a sample of 10 parents. An alpha coefficient of internal consistency was calculated as .86.

practice of these skills was rated as inadequate for a number of individuals. Half of the residents were reported to have expressed a wish for an intimate relationship.

In a follow-up study described earlier, Hellemans et al. (2010) compared a small group of 20 male adolescents and young adults with ASD and borderline/mild LD with 19 individuals with borderline/mild LD without ASD. No differences between the groups were found in theoretical knowledge or practice of self-care and socio-sexual skills, which were generally rated as adequate. There was no significant difference between the groups in reported interest in sexuality. The small numbers involved in this study did not produce a statistically significant difference, and it would be interesting to replicate with a larger sample.

In a Canadian study by Konstantareas and Lunsky (1997), fifteen adults with ASD and sixteen with LD were interviewed using an adapted version of the Socio-Sexual Knowledge, Experiences, Attitudes and Interests (SSKEAI) test⁶. The individuals with ASD were significantly less able to define sexual activities than the control group, and awareness of sexual terminology was correlated with level of cognitive functioning. There was a negative correlation between knowledge and endorsement of sexual activities, with the more knowledgeable endorsing fewer, possibly reflecting attitudes imposed on them by caregivers.

Lunsky and Konstantareas (1998) looked more specifically at the attitudes of people with ASD to sexuality. Their study interviewed four groups: individuals with LD, ASD (matched on age and level of cognitive functioning), undergraduate students and a community sample. A twenty-item questionnaire was used, adapted from the Socio-

⁶ Developed by Ousley and Mesibov (1991). Inter-rater reliability coefficient was reported as .98.

Sexual Knowledge and Attitudes Test (SSKAT)⁷, accompanied by illustrations.

Participants in the LD and ASD groups were shown pictures of activities or situations and asked to describe what was happening. They were then required to indicate verbally or non-verbally whether they thought the activity was 'OK' or 'not OK'. The ASD group were significantly more accepting of the socio-sexual situations than the group with learning disabilities. However, the attitudes of the ASD and LD group were more conservative than the university and community groups. For example, only half of the participants with ASD or learning disabilities approved of masturbation and pornography compared to nearly 100% of university and community participants. However, the sample sizes were small (sixteen and fifteen for the LD and ASD groups respectively), and with the use of just two responses of 'OK' or 'not OK', it is difficult to accept the results as a valid measure of attitude towards sexuality. Responses may have simply reflected personal preferences, participants' like or dislike of the pictures used, or attempts to please the interviewer.

In a recent study by Mehzabin and Stokes (2011), individuals with HFA and an age-matched typically developing (TD) group completed an adapted version of the Sexual Behaviour Scale (SBS). The HFA group reported significantly less knowledge of sex education than the TD participants. They also expressed more concerns for the future; two particular aspects mentioned were 'wet dreams' and 'when I get aroused', further suggesting a lack of information regarding physical sexual responses. The HFA group identified that they would benefit from more sex education. However, there was no significant difference between the HFA and TD groups on the scales measuring knowledge of privacy rules or level of public

⁷ Developed by Wish et al. (1980) to measure sexuality attitudes of people with mental retardation.

sexualised behaviour. The authors suggest that this lack of reported difference may be due to limited insight into the appropriateness of behaviour in the HFA group, and cite qualitative evidence to support this: one HFA participant reported seeking further privacy for 'sleeping' only, whereas many of the TD participants sought privacy for more intimate behaviours such as 'sex' and 'journal writing'. Interestingly the study found that age did not contribute significant variance; this suggests that socialisation and sexual education need to be addressed at a young age if the gap between HFA and TD individuals is to be bridged.

1.4.3. Sexual activity in adults

A number of studies have focused on the sexual activity and experiences of adolescents and adults with ASD, in comparison to other groups such as TD controls. Studies either use caregiver reports, or information directly from the individual.

Ousley and Mesibov (1991) looked at sexual attitudes and knowledge of adolescents and adults with HFA, and participants with HFA reported significantly fewer sexual experiences than a group with LD. Individuals with HFA reported considerable interest in sexuality, but aside from masturbation, the amount of sexual activities individuals with HFA engaged in was very limited; the authors suggest that this may indicate considerable sexual frustration.

In contrast, Konstantareas and Lunsy (1997) found no differences between their groups of participants with ASD and LD on level of sexual interest or experiences. However, the sample sizes were small (15 individuals with ASD and 16 with LD) and results varied considerably.

Stokes et al. (2007) collected information from the parents of 38 TD adolescents and adults, and 25 with ASD, using the Courting Behaviour Scale (CBS)⁸. They concluded that the reported level of romantic functioning of the ASD participants was significantly lower than that of their TD peers. Level of social functioning was found to have a significant influence on level of romantic functioning. Participants with ASD reportedly sought to initiate fewer romantic relationships, but across a wider range of people, such as colleagues, friends, strangers and celebrities. They were also reported to display a much wider variety of courtship behaviours.

Mehzabin and Stokes (2011), as described previously, gave questionnaires directly to TD young adults and those with HFA. Participants with HFA reported lower levels of social behaviours and fewer sexual experiences, in line with the findings of Stokes et al. (2007) above.

Van Bourgondien et al. (1997) sent questionnaires relating to sexual behaviours to group homes in North Carolina for adolescents and adults with ASD. Twenty seven homes responded, on behalf of 89 participants, covering the full spectrum of autism. Sixty eight percent of the sample were reported to masturbate regularly. However, most of these were male, and staff were unaware of masturbation occurring at all in 75% of females. One third of the sample engaged in person-oriented sexual behaviours, including kissing and holding hands, with obvious signs of sexual arousal. Attempts at sexual intercourse identified by staff were however rare. The majority of reported sexual behaviours occurred in the privacy of the individual's bedroom, bathroom or home, possibly due to the level of staff supervision in community

⁸ Cronbach's alpha indicated good reliability for the Social subscale and high reliability for the Romantic subscale.

settings. It is important however to note the limitations of using staff report measures; it is likely that the results represent an under-representation of the level of sexual activity of the individuals involved. In particular as the authors point out, female sexual responsiveness is less physically obvious, therefore difficult to observe and report.

Another study using information gathered from staff at group homes, Hellemans et al. (2007) focused exclusively on male adolescents and adults with HFA. Masturbation occurred frequently in the sample, although reported levels were lower than general population estimates. The majority of individuals used the privacy of bathrooms or bedrooms to masturbate. Seventy percent of those known to masturbate had been taught a masturbation technique, and frustration and unsuccessful attempts to masturbate were reported in two males (8%). Half of the individuals had experienced a close affective and/or physical relationship, although the sexual developmental level of these relationships had been limited. Three (13%) had experienced sexual intercourse (all with other males), again a lower frequency than general population figures. The number of bisexually oriented individuals was considered high in comparison to typically developing male adolescents and young adults; the authors suggest this could reflect an immature stage of sexual development, or the effects of living in largely male communities. Further longitudinal research would be needed to add clarity.

The follow-up study by Hellemans et al. (2010) found a similar profile of individuals with ASD, and no significant differences between the group with ASD and borderline/mild LD, and the group without ASD with borderline/mild LD. Significantly

fewer individuals with ASD had experienced a mutual relationship, and sexual intercourse. The two individuals with ASD known to have had sexual intercourse had done so with other males despite not being considered by caregivers to be homosexual. Of the fourteen participants with ASD whose sexual orientation was known, twelve were heterosexual, one bisexual and one homosexual. This fits more closely with general population figures than the previous study. However, given the small sample size of both studies, it is difficult to reach definitive conclusions.

1.4.4. Sexual issues and problematic sexual behaviour

Some studies have commented on particular issues and problematic behaviours related to sexuality in individuals with ASD, ranging from the use of objects during masturbation to stalking. Many of these are from the perspective of caregivers rather than the individual themselves.

Miyahara (2008) found that children in their group categorised as having a severe ASD were more likely masturbate in public, whereas those in the non-severe ASD group exhibited other problematic sexual behaviours such as chasing girls and talking about sex in public. They suggested that the type of problematic sexual behaviour could be influenced by the severity of ASD, although this study did not include control groups and therefore it is not possible to distinguish whether this is due to severity of autism itself or learning disability.

In the study by Ruble and Dalrymple (1993), a wide range of problematic sexual behaviours were reported by parents of children and adults with ASD; no significant association was found between verbal level and demonstration of sexual behaviours.

In terms of inappropriate behaviours in public, 65% of the sample were reported to have touched their private parts, 28% had removed clothing, and 23% had masturbated. Fourteen percent of the sample were reported to have used unusual objects during masturbation. Parents' concerns around sexuality were also explored; the main concern was about their child's behaviour being misinterpreted as sexual, followed by sexual behaviours being misunderstood. Sixty one percent of parents of females were concerned their child would become pregnant.

Mehzabin and Stokes (2011) found no difference in dysfunctional sexualised behaviour between HFA and TD young adults; however they highlight that the self-report measure they used may not have accurately captured the presence of such behaviour, particularly due to lack of insight into appropriateness of behaviour in the HFA group. Self-report is more helpful when validated by external reports, which this study did not provide.

Van Bourgondien et al.'s (1997) study looking at adolescents and adults with ASD living in group homes reported that 24% of their participants used objects directly during masturbation. The range of objects used was unusual, including eggs, books and stuffed animals. Around 9% of participants were reported to be sexually aroused indirectly by objects or other sensory stimuli, such as a suitcase, black shiny objects, shampoo bottles and coupons. Fifteen participants (17%) were reported to become sexually aroused looking at other people. Van Bourgondien et al. (1997) also looked at behaviour problems, using the Aberrant Behaviour Checklist, and their relationship with sexual behaviours. Individuals from this sample who masturbated were significantly more likely to engage in stereotypic behaviours, suggesting that

masturbation may be another form of stereotypic behaviour. There was no relationship between irritability, agitation or aggressive behaviour and masturbation, reaching orgasm or person-centred sexual behaviour. This does not support anecdotal caregiver reports that individuals whose sexual needs are not being met are more likely to be irritable and aggressive.

Group home caregivers in the study by Hellemans et al. (2007) reported peculiar masturbation techniques and the use of objects by two individuals (8% of the sample), who had experienced repeated unsuccessful attempts at masturbation. Three individuals (13%) occasionally masturbated in the presence of other people, and four (17%) demonstrated compulsive characteristics. Six individuals (25%) were noted to have a particular sexual interest in objects, and one of these met DSM-IV criteria for fetishism. In two people, sensory fascinations were associated with obvious sexual excitement. One individual met the DSM-IV criteria for paedophilia and received treatment in a specialist centre. Caregivers described sexual problems as 'severe' for seven individuals (29%); problems included masturbation in the presence of others, unwanted sexual touching, unwanted attempts at intercourse, and anxiety connected to sexuality. It is important to note the small numbers involved in this study, which limits generalisability to the wider population of individuals with HFA. All participants were living in group homes, and the authors propose that these institutionalised environments may affect the development and expression of sexuality.

The follow-up study by Hellemans et al. (2010) reported some similar findings. A specific interest in particular objects was noted for four individuals (20%) with ASD.

Partialism (a sexual interest in body parts) was reported in four individuals with ASD (20%) compared to none in the LD control group; a further two (10%) were sexually excited by olfactory fascinations. The group with ASD were significantly more aroused by 'usual' sexual stimuli such as pictures of naked women. Two of the individuals in the ASD group (10%) were primarily sexually attracted to prepubescent children, one of whom met the DSM-IV criteria for paedophilia; this was not reported within the control group. Five individuals with ASD (25%) were described as having severe sexual problems.

On the topic of stalking, Stokes et al. (2007) reported in their study that individuals with ASD attempted to initiate relationships with strangers and celebrities more frequently than typically developing peers. They also engaged in a number of inappropriate courtship behaviours not reported in the typical peers, such as touching, showing obsessional interest, monitoring the person's activities, making threats against them and threatening self-harm. These behaviours were directed indiscriminately across all types of target, suggesting that individuals with ASD were unable to discriminate between appropriate and inappropriate targets. They also persisted in their pursuit of relationships for significantly longer than typical peers when they received a negative response from the person or their family. These difficulties are likely to be due to lack of empathy and awareness of social norms. The authors suggest therefore that the individuals with ASD in this study appear to be "crossing the blurred line between normal courtship behaviour and stalking" (p. 1979), as their behaviours are likely to be experienced by others as intrusive. They concluded that individuals with ASD are at significant risk of negative consequences

and punishment due to indiscriminate and intrusive social and romantic relationship behaviours. However, the authors acknowledge the bias and potential inaccuracies associated with their methodology, of obtaining data purely from parents.

1.4.5. Long-term relationships

Only one study to date has looked at long-term relationships in people with ASD. A second recent study is reported within this section, which looks at the association between autism traits and various aspects of relationship satisfaction.

Renty and Roeyers (2007) recruited twenty one couples who had been married or cohabiting for at least one year, where the male spouse had a diagnosis of ASD. The couples filled in a battery of questionnaires looking at individual and marital adaptation, coping and support. For the men with ASD, less perceived social support from family, friends and acquaintances was associated with higher psychosocial distress. Marital adaptation was significantly associated with more received and perceived social support from the spouse, family, friends and acquaintances. For the women, fewer autism-specific traits in their partner were associated with higher levels of marital satisfaction. Individual adaptation was strongly related to received social support from family, friends and acquaintances, and women with high psychosocial distress received more support. Perceived and received support from their spouse was positively related to marital adaptation. Contrary to previous research on spousal support, there was a lack of significant association between spousal support and individual adaptation. The authors propose that this may reflect the social and communicative impairment of one spouse, and suggest further research is needed to identify other variables important to individual well-being in

such couples. However, marital adaptation was significantly associated with spousal support in both men and women, consistent with previous research highlighting the contribution of spousal support to relationship quality.

Interestingly formal support from professionals and services was not related to individual or marital adaptation in either the men or women. This has important clinical implications, as informal social support seems to have a more important effect on individual and marital adaptation. It is important, however, to note the small sample size used in this study, and therefore the limited statistical power. Longitudinal data was unavailable therefore causal relations between the variables could not be established. There was no control group for comparison, no qualitative data was collected, and the sample contained only males with ASD.

A recent project by Pollman et al. (2010) looked at the relationship between autistic traits (rather than a formal diagnosis of ASD) and marriage satisfaction in 195 Dutch newlywed couples. The Autism Spectrum Quotient (Baron-Cohen et al., 2001) was used to measure autistic traits, and a battery of questionnaires looked at relationship satisfaction and mediating factors such as self-esteem, attachment and intimacy. Men with more autistic traits reported less relationship satisfaction, however, the partner's autistic traits were not related to relationship satisfaction in either gender. This is in contrast to the findings of Renty and Roeyers (2006), and the authors suggest that autistic traits may only have a significant impact on the relationship if they reach clinical levels. The link between autistic traits and relationship satisfaction in male participants was mediated by responsiveness towards the partner, trust in the partner and intimacy in the relationship.

1.5. Discussion

1.5.1. Summary and clinical implications

The difficulties people with ASD experience with social interactions may negatively impact on the development of sexuality. There are also indications that people with ASD find adapting to the physical changes of puberty difficult. IQ and verbal skills seem to be a good predictor of sexual knowledge, however people with ASD may have less sexual knowledge than typically developing controls. Many individuals with ASD demonstrate an interest in sexuality, however they report limited sexual experiences and romantic behaviours. Masturbation is common, although this may have to be explicitly taught by caregivers, and the use of unusual objects during masturbation has been reported. This may relate to stereotyped behaviours associated with ASD. People with ASD may be more likely to display inappropriate sexual behaviours in public, and sometimes the use of inappropriate courtship behaviours with limited social awareness can cross the boundary into stalking. Institutionalised environments may also contribute to limited opportunities for sexual intercourse, and a higher than expected occurrence of same-sex intercourse. Information about long-term relationships is sparse, however there is some suggestion that higher autistic traits in men can negatively impact on relationship satisfaction for one or both partners. Informal social support is reported to be particularly important for these couples.

The literature demonstrates that sexuality and relationships are important to people with ASD, however the social difficulties associated with ASD can impact on individuals' ability to express these desires appropriately. Families, carers and

support services may need to provide additional guidance during puberty and early adulthood, by teaching masturbation techniques and providing support to channel sexual and romantic interests into socially appropriate avenues. Specialist support may be required when unusual sexual interests impact on other people. Services should also endeavour to strengthen the informal social support networks available to individuals and their partners where applicable, which are an important factor for people with ASD in long-term relationships.

1.5.2. Critique of research

A well acknowledged criticism of research in this area is small sample sizes. Many studies use groups of approximately 20 individuals, and therefore results lack statistical power. It is possible that the sensitive nature of the topic area deters people from participating, particularly as parents or carers are often approached rather than the individual themselves.

A number of studies in this area look at sexuality across the spectrum of ASD. However, ASD encompasses a diverse range of individuals, ranging from those with a severe LD to those with a typical IQ, therefore it does not seem sensible to draw conclusions on the basis of research spanning the range of functioning, particularly when small sample sizes are used. Many recent studies have focused on people with HFA for whom relationships in particular may be most relevant.

The studies used in this review are very male-focused, indeed many contain only male participants. This may be largely due to the low ratio of females with ASD (e.g., Volkmar et al., 2003), particularly at the high-functioning end of the spectrum, where

relationships are perhaps most likely to occur. However, there seems a clear need to look further into gender differences, as sex education programmes are being designed on the basis of male-dominated research, and these may neglect the specific needs of female individuals.

The research discussed here originates from a range of countries, and diagnostic methods differ. There may be participants included in some studies who would not meet the criteria for others, which makes the results difficult to interpret as a whole. Also cultural differences may account for variation in the reporting of sexual interest and behaviour.

Many studies use parents or carers for data collection, either via questionnaires or interviews. There is an obvious problem with the reliability of people reporting the experiences and behaviours of others, particularly related to areas of life usually considered private in typically developing individuals. This seems especially relevant to people with HFA who have a higher level of independence and whose private behaviours may be even less known to their carers. Many studies also draw samples from group homes perhaps due to ease of access to participants. However, responses may reflect institutionalised patterns of behaviour, and cannot necessarily be generalised to the wider population of people with ASD living in community settings. The research raises important ethical concerns regarding the reporting of such private behaviours by caregivers; individuals have the right to privacy and their sexual choices should be respected without being formally recorded and scrutinised.

Much research directly involving people with a LD struggles to find methodology to reflect the experiences of the participants accurately, often due to difficulties with

language and communication. It has been suggested that theory of mind is needed for self-consciousness, therefore people with ASD who typically have difficulty with theory of mind struggle with introspection and describing their inner world (e.g., Frith and Happé, 1999). However, people with HFA generally have a more developed theory of mind, and are better able to describe their inner experiences, which has been reflected in more recent studies (Mehzabin and Stokes, 2011). There seems to be a place for more qualitative research, directly exploring the experiences and desires of people with ASD, as currently most of our knowledge on this topic is based on the reports of other people⁹.

The studies in this review which report problematic sexual behaviours do not use typically developing control groups, therefore it is unreasonable and unfounded to conclude that these behaviours are more prevalent amongst individuals with ASD. The accuracy of measuring sexual behaviours and preferences in the general population is questionable (e.g., McAuliffe et al., 2007) confounded by the fact that most sexual behaviour is not publically observable. Most studies included in the review rely on parent or carer reports; the sexual behaviour of the individuals may be more observed than their typically developing peers, due to lack of understanding of privacy and social rules. Therefore without accurate estimates of prevalence of such behaviours in the general population, the research presents an unjustifiably negative picture of the sexuality of individuals with ASD.

⁹ See the reflective paper within this thesis, which explores the relevance of qualitative research to this population in more detail.

1.5.3. Areas for future research

All of the studies examined in this literature review rely on one perspective, primarily that of a parent or carer, or in some cases the perspective of the person with ASD. As Mehzabin and Stokes (2011) point out, there is a need for 'triangulated studies' looking at parental or caregiver reports, the perspective of the individual and observational accounts by the researcher. This would eliminate informant bias, and help researchers get closer to the actual experiences and needs of people with ASD, although it is important to acknowledge the considerable variation present in this diverse population.

Females have been largely neglected by the research to date, and it would be interesting to see a study examining the sexual and/or relationship experiences of females with ASD, or specifically focusing on gender differences. This would allow for better provision of gender appropriate sex education and support.

Much more research is needed on the experiences of people with ASD and their partners within long terms relationships and marriage. There is considerable anecdotal information from autobiographical accounts to suggest that people with ASD do have long-term relationships, and this is an area worthy of attention. However, to date only one empirical paper (Renty and Roeyers, 2006) has focused directly on this topic. It would also be useful to look at partners' perspectives, in order to better understand difficulties in reciprocation and sexual interactions. This would inform more appropriately targeted support and interventions.

There is a growing body of research looking at the provision of specialised sex education programmes for people with ASD - see Tissot (2009) and Nichols and Blakeley-Smith (2010). Many children with HFA however are educated in mainstream schools (Harbinson and Alexander, 2009) due to their average or above average IQ. As part of mainstream education, they receive a programme of sex education; however this review indicates that sex education for people with ASD should have an increased focus on social interaction, which is linked to level of sexual functioning (Stokes and Kaur, 2005). Future research could focus on the usefulness of mainstream sex education for adolescents with HFA, and the possible development of an evidence-based specialist programme to address the needs not met by existing educational provisions.

1.6. References

References used in the literature review are indicated by a *.

Attwood T (2006) *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley Publishers.

Baron-Cohen S, Wheelwright S, Skinner R, Martin J and Clubley E (2001) The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/high functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders* 31: 5-17.

Engström I, Ekström L and Emilsson B (2003) Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism* 7(1): 99-110.

Frith U (2003) *Autism: Explaining the Enigma (2nd Ed.)*. Oxford: Blackwell Publishing.

Frith U and Happé F (1999) Theory of mind and self-consciousness: What is it like to be autistic? *Mind and Language* 14(1): 1-22.

Harbinson H and Alexander J (2009) Asperger syndrome and the English curriculum: Addressing the challenges. *Support for Learning* 24(1): 11-18.

*Hellemans H, Colson K, Verbraeken C, Vermeiren R and Deboutte D (2007) Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders* 37: 260-269.

*Hellemans H, Roeyers H, Leplae W, Dewaele T and Deboutte D (2010) Sexual behavior in male adolescents and young adults with autism spectrum disorder and borderline/mild mental retardation. *Sexuality and Disability* 28: 93-104.

Hénault I (2005) *Asperger Syndrome and Sexuality: From Adolescence Through Adulthood*. London: Jessica Kingsley Publishers.

Hendrickx S and Newton K (2007) *Asperger Syndrome – A Love Story*. London: Jessica Kingsley Publishers.

Howlin P, Goode S, Hutton J and Rutter M (2004) Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* 45(2): 212-229.

*Kalyva E (2010) Teachers' perspectives of the sexuality of children with autism spectrum disorders. *Research in Autism Spectrum Disorders* 4: 433-437.

*Konstantareas MM and Lunsy YJ (1997) Sociosexual knowledge, experience, attitudes and interests of individuals with autistic disorder and developmental delay. *Journal of Autism and Developmental Disorders* 27(4): 397-413.

Levesque MJ, Nave CS and Lowe CA (2006) Toward an understanding of gender differences in inferring sexual interest. *Psychology of Women Quarterly* 30: 150-158.

*Lunsy Y and Konstantareas MM (1998) The attitudes of individuals with autism and mental retardation towards sexuality. *Education and Training in Mental Retardation and Developmental Disabilities* 33(1): 24-33.

McAuliffe TL, DiFranceisco W and Reed BR (2007) Effects of question format and collection mode on the accuracy of retrospective surveys of health risk behavior: A comparison with daily sexual activity diaries. *Health Psychology* 26(1): 60-67.

*Mehzabin P and Stokes MA (2011) Self-assessed sexuality in young adults with high-functioning autism. *Research in Autism Spectrum Disorders* 5: 614-621.

*Miyahara H, Inadomi H, Ohta Y, Aikawa K and Ozawa H (2008) Mothers' perceptions of the sexual development and behavior of their children and persons with autism in general. *Acta Medica Nagasakiensia* 53: 1-7.

Müller E, Schuler A and Yates GB (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism* 12(2): 173-190.

Nichols S and Blakeley-Smith A (2010) "I'm not sure we're ready for this...": Working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. *Social Work in Mental Health* 8: 72-91.

Orsmund GI, Krauss MW and Seltzer MM (2004) Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders* 34(3): 245-256.

*Ousley OY and Mesibov GB (1991) Sexual attitudes and knowledge of high-functioning adolescents and adults with autism. *Journal of Autism and Developmental Disorders* 21(4): 471-481.

- *Pollman MMH, Finkenauer C and Begeer S (2010) Mediators of the link between autistic traits and relationship satisfaction in a non-clinical sample. *Journal of Autism and Developmental Disorders* 40: 470-478.
- *Renty J and Roeyers H (2007) Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Journal of Autism and Developmental Disorders* 37: 1247-1255.
- *Ruble LA and Dalrymple MS (1993) Social/sexual awareness of persons with autism: A parental perspective. *Archives of Sexual Behavior* 22(3): 229-240.
- Seltzer MM, Shattuck P, Abbeduto L and Greenberg JS (2004) Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities* 10: 234-247.
- Slater-Walker C and Slater-Walker G (2002) *An Asperger Marriage*. London: Jessica Kingsley Publishers.
- Sperry LA and Mesibov GB (2005) Perceptions of social challenges of adults with autism spectrum disorders. *Autism* 9(4): 362-376.
- Stanford A (2002) *Asperger Syndrome and Long-Term Relationships*. London: Jessica Kingsley Publishers.
- *Stokes MA and Kaur A (2005) High-functioning autism and sexuality. *Autism* 9(3): 266-289.

- *Stokes MA, Newton N and Kaur A (2007) Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders* 37: 1969-1986.
- Tissot C (2009) Establishing a sexual identity: Case studies of learners with autism and learning difficulties. *Autism* 13(6): 551-566.
- *Van Bourgondien ME, Reichle NC and Palmer A (1997) Sexual behavior in adults with autism. *Journal of Autism and Developmental Disorders* 27(2): 113-125.
- Volkmar FR, Szatmari P and Sparrow SS (1993) Sex differences in pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 23(4): 579-591.
- Wish JR, McCombs KF and Edmonson B (1980) *The Socio-Sexual Knowledge and Attitudes Test*. Wood Dale: Stoeling Co.
- World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. Geneva: WHO.

CHAPTER TWO

An exploration of friendship in adults with Asperger syndrome or high functioning autism

Word count: 5996 (excluding tables, references and footnotes)

2.1. Abstract

Friendships are thought to play a significant role in child development and subsequent mental and physical health in adulthood. People with autism spectrum disorders (ASD) experience various difficulties accessing and maintaining social relationships across the lifespan, and research has questioned the value of friendships to this group. Qualitative interviews were carried out with six adults with Asperger syndrome (AS) or high-functioning autism (HFA), recruited via a voluntary organisation, and the transcripts were then examined using Interpretative Phenomenological Analysis (IPA). The analysis highlighted the following super-ordinate themes: definition of friendship, maintaining friendships, difference, maturity and increasing self-awareness, and future desires. The participants clearly valued friendships and were able to describe the functions they served, and a major clinical implication of the study is the importance of supporting adults with ASD to access and maintain friendships. The results are discussed in relation to the existing literature base, and the limitations of the qualitative methodology used are considered. Suggestions for future research include the use of triangulation to explore multiple perspectives of friendship, and an examination of gender differences around friendship.

2.2. Introduction

2.1.1. Asperger syndrome and high-functioning autism

Asperger syndrome is a form of autism which affects individuals' abilities to make sense of the world, process information and relate to people. The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA, 1994) provides criteria for the diagnosis of Asperger's disorder, which includes the following: qualitative impairment of social interaction; restricted repetitive and stereotyped patterns of behaviour, activities and interests; and clinically significant impairment in social, occupational or other important areas of functioning. There is however considerable debate about the differentiation of the subcategories of autistic spectrum disorders (ASD)¹⁰.

The general consensus is that autism and Asperger syndrome are both variants of the same underlying developmental disorder (Frith, 2003); if an individual with autism has an IQ within or above the normal range, they are said to have high-functioning autism - HFA. If individuals meet all the criteria for HFA except communicative abnormality or history of language delay, they are said to have Asperger syndrome - AS (Baron-Cohen, 2000). Diagnosis of AS/HFA has tended to be much later than other forms of autism, often in adolescence or adulthood (Punshon et al., 2009).

¹⁰ Some researchers have argued for the upcoming DSM V either to remove 'Asperger's disorder' or substantially revise the diagnostic criteria (Ghaziuddin, 2010). Others, for example Boomsma et al. (2008) have proposed a symptom-based model.

Difficulties in social communication and interaction are characteristic features of AS/HFA. Landa (2000) describes some of the difficulties individuals with AS/HFA experience in the social use of language, including an idiosyncratic form of expressing intentions, failure to adjust language in response to changing contextual cues, and difficulty using eye contact to establish joint attention. Conversation may be one-sided, and individuals often react inappropriately to the affective context of the exchange due to difficulty recognising emotions, giving the impression of insensitivity or formality (Klin and Volkmar, 1997).

2.1.2. Friendship

Friends can be defined as people we like and with whom we enjoy doing things (Dwyer, 2000). Although friendships can vary hugely, some common elements include sociability - sharing social activities and providing a means of expressing one's individuality -, practical support, emotional support and confirmation of identity (Allen, 1996). Friendship varies significantly across the lifespan; peer relationships are thought to play a significant role in children's social and cognitive development (Ladd et al. 1996, Kutnick and Kington, 2005), therefore they can have a lifelong impact.

Much research has focused on the importance of friendship during adolescence, when children begin to discover independence and move away from the family unit (Allen, 1996). For example Demir and Weitekamp (2007) found that friendship quality predicted happiness in adolescents above and beyond personality variables. Less research has looked at the continuing role of friendship in adulthood, however it has

been identified as a protective factor against depression (Powers et al., 2009). The presence and quality of friendships can also have a positive effect on individuals' physical health, for example, cardiovascular activity (Holt-Lunstad et al. 2007). Friendship clearly serves important functions in typically developing individuals.

2.1.3. Friendship in AS/HFA

Much of the research on friendship in AS/HFA focuses on the difficulties faced by individuals, primarily using questionnaires. Bauminger and Kasari (2000) found that children with autism were lonelier than typically developing controls, and reported a poorer quality of friendships in terms of security and companionship. Koning and Mogill-Evans (2001) reported that adolescent males with AS had poorer social skills, fewer friends and lower social competence than matched controls. A recent study by Whitehouse et al. (2009) found a poorer quality of best-friendship in adolescents with AS compared to typically developing controls, less motivation to develop friendships, and higher levels of loneliness and depression. Individuals with AS/HFA may actively avoid friendships in childhood, but become increasingly anxious to be accepted and join in social groups as they grow older (Howlin, 1997). Baron-Cohen and Wheelwright (2003) concluded that although adults with AS do have friendships, their relationships are reported to be less close, supportive and less important to individuals than those in the general population.

A number of follow-up studies have looked at outcomes for adults with AS/HFA, and have reported mixed findings; Jenness-Coussens et al. (2006) found that young men

with AS reported a lower quality of life than controls, however they had similar levels of social contact and friends. Howlin (2000) summarised that social contact in adults with AS/HFA is typically more centred around special interests, and often the pressure to 'fit in' leads to stress and anxiety. An individual's social environment such as work and domestic circumstances greatly influences opportunities for friendship (Allen, 1996), and as these are often limited in individuals with AS/HFA, it is possible that this contributes to isolation.

Much of the previously described research fails to explore the qualitative experiences of friendship. The literature contains a number of first-person accounts from individuals with AS/HFA, and their thoughts about friendships, which have a more positive slant (e.g., Lawson, 2006). An exploratory study of an adolescent male with AS demonstrated he had a basic understanding of the concept of friendship, desired friends and enjoyed some aspects of those relationships (Howard et al., 2006). Carrington et al. (2003) found that five adolescents with AS found the concept of friendship hard to describe. A recent qualitative study by Daniel and Billingsley (2010) looked at experiences of friendship in boys with ASD aged 10-14; they all reported having friends, although they identified difficulties establishing them. Müller et al. (2008) explored social challenges and supports from the perspective of adults with AS/HFA, and highlighted an intense sense of loneliness.

2.1.4. Gaps in the literature and implications

There is little literature on friendship patterns in adults with AS/HFA. The research described above suggests they may have fewer and poorer quality friendships, as defined by traditional concepts of friendship. It is however unclear how individuals with AS/HFA feel about this and whether they perceive this to be a problem, as is the presumption in the literature. It is also not clear how adults with AS/HFA initiate and maintain friendships, given their often limited social environments. Because diagnosis of AS/HFA is often not made until adolescence or adulthood, social interventions targeted at children with ASD have not typically been available to these individuals. As friendship has an important role in the general well-being of typically developing adults, it seems important to consider friendship in adults with AS/HFA, so that support and interventions can be tailored to the identified strengths and needs in this area.

2.1.5. Aims

The aims of the study are to explore the nature and value of friendships in the lives of a small group of adults with AS/HFA. Positive experiences and difficulties encountered will be explored, with reference to friendships across the lifespan. The experiences captured will be considered in relation to existing research, and used to make clinical recommendations.

2.2. Methodology

2.2.1. Design

Due to the lack of previous research, and the focus on experiential data rather than clearly measurable concepts, a qualitative design was employed for the study.

The qualitative approach chosen for this study was Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). This particular method was chosen because the aim was to explore and describe individuals' experiences, and attempt to capture the meanings they attribute to them, based on their own interpretations of these phenomena.

2.2.2. Materials

An interview schedule was prepared in order to provide a basic structure for each interview (see Appendix D), based on guidelines suggested by Smith et al. (2009). The questions were purposefully open questions to encourage in-depth responses.

Additional sub-questions were included as prompts for any participants who found it difficult to talk at length on any of the topics. The schedule was used flexibly to guide the coverage of relevant material, and additional questions were used in response to topics raised by participants.

2.2.3. Participants

Participants for this study were recruited from a purposive sample of adults connected with a regional ASD charity. The inclusion criteria were that participants were aged 18 or over, and had received a diagnosis of either AS or HFA. It was not possible to check medical records, therefore all information regarding diagnosis was obtained directly from the participant.

The participants were six adults, age range 20 to 44, mean age 34. There were five males and one female, with a diagnosis of either AS or HFA. The average age at which a diagnosis was received was 22. Table 1 provides further demographic and diagnosis-related information about each participant.

Participant	Gender	Age	Diagnosis	Age at diagnosis	Ethnicity	Marital status	Living situation
James*	M	44	AS	23	White British	Single	Living alone
Marie	F	39	AS	32	White British	Married	Living with spouse
Paul	M	20	AS	7	White British	Single	Living with family
Simon	M	35	HFA	11	British	Single	Living alone
Aaron	M	26	AS	21	White British	Single	Living with family
George	M	39	AS	38	White European	Single	Living alone

Table 1. The six participants. AS = Asperger Syndrome, HFA = High Functioning Autism. *Pseudonyms have been used to preserve anonymity.

2.2.4. Procedure

2.2.4.1. Ethical approval

Ethical approval for the study was granted by Coventry University Ethics Committee.

See Appendix A.

2.2.4.2. Recruitment

Potential participants were approached by a member of staff from the voluntary organisation, either during a support group meeting or individually. They were given an information leaflet (see Appendix B) containing details of the study. Attached to the information leaflet was a contact details form (see Appendix B), for people interested in taking part to return to the main researcher. On receipt of this, potential participants were contacted using their preferred medium as indicated on the form (telephone or post) to arrange an interview. Participants were informed that they would be entered into a prize draw to win a £20 voucher.

2.2.4.3. Data collection

Participants were interviewed at the venue of the voluntary organisation; interviews lasted approximately one hour. Breaks were provided if requested. The interviews were conducted in a private room to maintain confidentiality. One participant requested that a member of staff sit in the room during the interview, which was accommodated.

Prior to the interview, participants were prompted to re-read the information sheet outlining the purpose and nature of the study, and an additional verbal explanation of what would be involved was given. Time was allocated for discussion of this information, and it was stressed that participants were free to withdraw from the study at any time. Participants were then asked to sign a consent form (see Appendix C), giving permission for their interview to be included in the research study. They

were also asked to fill in a basic information sheet providing demographic information and details about their diagnosis (Appendix C). Each interview was digitally audio-recorded. Following the interview, participants were provided with a verbal debrief, and given the opportunity to discuss the interview and ask questions. No participants reported any immediate distress, however they were given a copy of the information sheet which included details of a professional to contact in the event of distress experienced as a result of the interview.

Following completion of the interviews, the recorded data was transcribed verbatim. Each transcript was given a code, and all identifying information including names was changed to maintain anonymity.

2.2.5. Data analysis

In order to analyse the qualitative data using Interpretative Phenomenological Analysis (IPA), the computer software QSR NVIVO (2009) was used for the storage and coding of the transcripts. The process described by Smith et al. (2009) was followed in order to identify emergent and super-ordinate themes. See Appendix E for a summary of the analytic process and an example of coded transcript. Sections of transcript were also read by a second member of the research team and a researcher unconnected with the project but familiar with IPA, in order to check the validity of the identified concepts and themes using triangulation.

2.2.6. Subjectivity

The primary researcher is a trainee clinical psychologist with both professional and personal experience of AS/HFA. A particular interest of the researcher is how people with AS/HFA function as adults. The researcher has noticed a trend in the research to compare individuals with AS/HFA unfavourably with typically developing adults, and highlight poor social outcomes. This seems at odds with professional and personal observations of successful and valued friendships and relationships, therefore there may have been some bias towards focusing on these positive experiences. However, the interviews were conducted according to IPA guidelines, and a triangulation procedure was used to ensure the validity of the analysis (see above).

2.3. Results

Following analysis of the transcripts, five super-ordinate themes were identified, with further subordinate themes within each one. These are illustrated in Table 2, and discussed in more depth below. Quotations are presented in italics, followed by the participant's pseudonym and line number of the transcript in brackets.

Super-ordinate theme	Subordinate theme 1	Subordinate theme 2	Participants within each theme
Defining friendship	Sources	School and education Church Family Gender and age mix	J, M, P, S, A, G J, M J, M J, M, P, S, A, G
	Levels of friendship	Acquaintances Close friends and best friend	J, A, G J, M, P, A
	Function	Helping me out Sharing ideas and feedback Reducing introversion Visiting places/shared interests	J, S, A A G J, M, S, A, G
	Qualities of friendship	Friendship is important Honesty and trust Closeness and openness Acceptance and feeling understood	J, P, A, G J, M, P, S, A, G M, P, A J, M, P, G
Maintaining friendships	Ways of keeping in touch	Telephone Social networking	J, M, S, A, G J, M, S
	Frequency of contact	Difficulties arranging meeting up Friendship takes time to establish Physical distance Would like more contact	J, M, A J, M, S, G M, S, A J, M, G
	Barriers	Barriers and emotion regulation ASD related social difficulties Finances	M, S, G J, M, S, A, G J, G
	Rejection	Contact not returned Friends have other priorities Let down by friends	J, M J, M, G J
	Ruptures	Falling out with friends Apologising Losing touch with friends	J, M, P, S, A, G J, P, A J, M, P
Difference	ASD and others	ASD is a spectrum Treated as stupid Social awkwardness	M, S, G S, A J, M, A, G
	Vulnerability	Bullied due to AS	J, P, A, G
Maturity and increasing self-awareness	School experiences	Mixed enjoyment School friends Experience of a special school	J, S, A, G J, M, P, S, A A
	Increasing self awareness	Efforts to learn social skills Learnt from experience Diagnosis changed perspective	G J, M, A G
	Changes with age	Friendship easier with age Fewer opportunities with age	J, P, G J
Future desires	Meeting new people	Satisfaction with current friends Opportunities to meet people	J, P, S, A J, M, S
	Relationships	Friendship can lead to dating Concerns about relationships	J, M, S J

Table 2. Super-ordinate and subordinate themes identified by the analysis. *J =

James, M = Marie, P = Paul, S = Simon, A = Aaron, G = George.

2.3.1. Defining friendship

2.3.1.1. Sources

Friendships included a mix of genders and ages. Participants reported friendships from a wide variety of sources, such as education (including school and college), family and friends through church:

“Um, well one of my best friends, I’ve known him for ten years now, um... I met him when I was in my last year of school, um... er, I did my Duke of Edinburgh’s awards with him at um, a local um, activity centre. And, you know, we did our expeditions together. Um, we’ve stayed in touch, you know, even though we both went to uni, different unis.” (Aaron; 7)

2.3.1.2. Level of friendship

Overall, participants felt that friendship was an important part of their lives. Different levels of friendship were discussed, for example, George was clear that acquaintances were different to friends, however he struggled to articulate what differentiated them. He described feeling more uncomfortable around acquaintances.

“I just feel that I’d have to sort of... sort of work at it a bit harder.” (George; 170)

Marie talked about colleagues she had previously worked with who she wouldn’t describe as friends.

“‘Cause they’re just... I don’t know, don’t think we’d really get on, or they’re not really interested in the sorts of things that I’m interested in.” (Marie; 156)

2.3.1.3. Functions

Participants identified a number of functions of friendship, for example helping with problems, and providing support during difficult times.

“I think for me, friends are, they’re probably like more the first people I would contact really if um, I felt I had a problem or if I wanted to invite them.” (Aaron; 85)

George described how friendship reduces his tendency to introversion and negative thinking.

“One thing I do always struggle against is going too far into my own head, and that’s the sort of counterbalance to that.” (George; 182)

“It sort of helps in terms of not allowing me to get into a more negative thinking and more depressive thinking, which I can do.” (George; 186)

He also talked about the importance of friendship during the transition from adolescence into adulthood.

“I think it’s about that sort of move to independence is vital to have friendships and other support structures as well, ‘cause that’s how everyone else lives.” (George; 329)

2.3.1.4. Qualities of friendship

Openness and honesty were identified as important qualities of friendship. Aaron

described his relationship with a close friend, and how he valued feedback.

"It's just er, a very good open relationship and it's also one where we can be honest with each other, so if, if one of us is doing something that the other one doesn't like, they'll tell us and they'll know it's, it's nothing personal." (Aaron; 24)

Feeling understood and accepted by friends was highlighted.

"I think it's just a feeling about feeling comfortable and accepted, those are the sort of key things." (George; 159)

"Being able to talk, to share, to talk to other people and them understand what I'm going through." (Marie; 99)

Shared interests were unanimously mentioned as an important factor, although James acknowledged that this in itself was not enough.

"But I think for me, it's not just having the same interests that con-constitute a friendship." (James; 253)

2.3.2. Maintaining friendships

2.3.2.1. Ways of keeping in touch

Telephone and e-mail were a commonly cited way participants use to keep in touch with friends. Social networking sites were also mentioned as a way of getting in touch with old friends and maintaining friendships:

"I mean, because there's people through youth group that I'm sort of friends with on Facebook that I haven't seen for a long time." (Marie; 250)

2.3.2.2. Frequency of contact

A number of difficulties were mentioned with regards to the frequency of contact with friends. Both Marie and James identified that they would like to see their friends more regularly:

"I would like to see people more often, the people that I have, I haven't seen for ages, like the friend that lives in Rugby for example." (Marie; 223)

One of the reasons given for infrequent contact was physical distance from friends.

"There's a few people I, I just haven't seen for, for a long time because they don't live locally and we don't meet up very often." (Marie; 35)

Several participants also talked about the difficulties co-ordinating times with friends to meet up:

"But it's when people can meet up you see, so you're sort of having to make appointments." (James; 901)

There was acknowledgement that friendship takes time to establish, and is not something that happens instantly:

"Like in any relationship it's trying to find, it's the, the early, the first few weeks, first few months. Then once the person actually knows you, if they feel a bit more relaxed, and be more open, then they will tell you, 'oh I like this, that and the other', besides the basics." (Simon; 108)

"So this is why you sort of establish things over years, so... so you get to talk to people over sort of a long period of time, and that sort of helps rather than, I'm not instant friends, it's something I can't do." (George; 206)

2.3.2.3. Barriers

There were a number of barriers highlighted to maintaining friendships. George talked about the impact of his inflexibility.

"I can be quite black and white in terms of... if you do something wrong, then it's hard for me to sort of... forgive people easily as well, I find it very hard to let go of things." (George; 368)

James described how some features of AS could make friendships more difficult.

These included not being able to understand sarcasm, or read between the lines.

"With people with Asperger's it's harder [cough], because they don't sort of know the social, um... unwritten rules, and they find it difficult to be naturally intuitive, or naturally um, considerate to other people, the needs of other people." (James; 604)

Only two of the participants were in some form of paid employment, and finances were a barrier to socialising more.

"I'd like to be doing more on the social front, but then because I'm unemployed I don't have a lot of money and, I worry about spending money and it... it becomes a bit of a cycle, where I don't want to do anything because I worry about that." (George; 138)

2.3.2.4. Rejection

The theme of rejection came into several interviews. Marie described several attempts to contact old friends, which were not reciprocated:

"I've tried to send her a message on Friends Reunited and I had no response... Perhaps she just doesn't approve of the fact that I divorced and then remarried, I don't know. [sighs] Oh, I don't know the reasons." (Marie; 181)

Participants recognised that friends often have other priorities:

"And as I said, other people have got children so they don't have that much time. And then working full time as well, a lot of them." (Marie; 135)

"Obviously John and Claire have a family and all that, those things, so there's only like so much time you can pop in for a cup of tea and things, and then sort of move on." (George; 59)

James talked about the sadness of being let down by friends:

"God will never let you down but other humans, humans will. That's one thing that I've had to learn throughout life...and it hurts when people let you down." (James; 65).

2.3.2.5. Ruptures

Ruptures within friendship had been experienced by many of the participants. For George, falling out had been an emotionally traumatic experience.

"I've had fallings out where you know, we just don't, I don't bother with them anymore because it's not ... it's too... sort of er painful and difficult, and again once the trust goes it's hard to... let people back in." (George; 373)

Aaron however was able to look at these quite philosophically.

"Plenty of fallings out, I mean, just difference of opinion or... er... someone has done something or said something that the other one hasn't liked, and um... it, I mean this was more the case... you know, when I was approaching my teenage years when you'd fall out with your friends over stupid things really, and... after a while you'd make up and then, I suppose it's only really now... you look back and think, why, why did I do that (laughing), you know, why did we fall out over that, it was just plain stupid really." (Aaron; 154)

Both Aaron and Paul recalled occasions when they had apologised following arguments with friends.

"I said, I said sorry for er, er, for some of the slightly inappropriate things that I've done." (Paul; 128)

Losing touch with friends, and sadness at drifting apart, were common experiences.

"I have e-mailed him recently but he hasn't replied, so obviously he must be sort of, at a distance, and we just suddenly sort of lost touch with each other. This is what happens when people, sort of, move on." (James; 207)

2.3.3. Difference

2.3.3.1. ASD and others

When talking about her upcoming birthday party, Marie distanced herself somewhat from her diagnosis.

"Some people with my disability, we're all different so some of us are more severe than others, and I think maybe some people wouldn't have, have hardly

any friends and might not even have, like, I don't know whether they'd have a birthday party." (Marie; 325)

Both Aaron and Simon recalled times they had been treated by others as stupid because of their diagnosis.

"If other, regular people made mistakes, it was like, 'oh it's OK, it's what you do', and when it was me, it was like, 'oh for God's sake', and you know, it was, it was sort of, I think people seemed to think ... maybe I was doing it deliberately or... I was, I was too thick to... you know, know any better really." (Aaron; 144)

2.3.3.2. Bullying and vulnerability

Bullying and teasing at school had been common experiences, as a result of being viewed differently by other children.

"I was often getting the, the taunt of like, you know, spastic, spacca... you know, thicko and er, and all the rest of it really. I don't know whether it was just, you know, ignorance or people just thinking, 'oh he's different, let, let's have him'." (Aaron; 102)

2.3.4. Maturity and increasing self awareness

2.3.4.1. School experiences

Participants reported mixed experiences of school. Aaron talked about his experience of going to a special school, including the lack of preparation he felt for life after school:

"When I was at school. It was a bit of a bubble... um, if you would, because our school teachers would be saying, you know, you know the world's like a rosy, you know, very rose tinted spectacles and, you know, everything would work out OK but, I was growing up on a run-down council estate and I was seeing exactly the opposite." (Aaron; 112)

"It wasn't probably 'til a couple of years later that I realised, actually, it didn't prepare me for the outside world at all." (Aaron; 132)

2.3.4.2. Increasing self-awareness

George only received his diagnosis aged 38 and described his lifelong search to understand why he struggled so much with social interactions. This involved undergoing various types of counselling, and making deliberate efforts to increase his social skills:

"Well I put myself in situations where I had to learn skills, like I did voluntary work with an organisation that worked with young offenders, and they did a lot of... they had a walk and talk philosophy to them, which is what they put the kids through, they put you through as well in terms of you try and sort of work through one or two issues and things, so... and from them, I learnt some counselling skills through them." (George; 96)

Learning from mistakes and experience was something James and Marie related to.

"I mean I'm sure that I'm more savvy as an adult, I'd say at 44, somebody tells me something, I think well, you know, I'll believe the evidence when I see it. I don't sort of take things on face value. I've learnt how to be a bit more discerning and a bit more circumstance, a bit more streetwise than I used to be." (James; 986)

"I suppose over the years I've learnt to be careful about what, who I talk to and what I tell them really, and... 'cause I think... [sighs] when I was younger, I was more naive about, you know, trusting people and telling people things and I'm more wary now." (Marie; 142)

2.3.4.3. Changes with age

Overall, participants felt that learning from experience had helped develop their social awareness, and as a result friendships were easier with age. However, James reported that it was difficult to find situations in which he could meet potential friends:

"I find them [friendships] easier, but I find the opportunities are less." (James; 732)

2.3.5. Future desires

2.3.5.1. Meeting new people

The general consensus was that the participants would like more friends. Simon illustrated this point with reference to his favourite film:

"You're probably not into Star Wars, but a quote in one, one of the characters said, um, in the second Star Wars film, 'I want more'." (Simon; 92)

Many participants had given thought to how they might go about meeting new people in the future, for example, joining interest groups:

"I think I'd probably look at um, joining groups that reflect my own interests more than anything. I'd probably see if, you know, there was, you know, any groups going around that's maybe seeking new members." (Aaron; 167)

There was also recognition that making new friends could happen more naturally:

"I meet people through, through friends you see, like through other friends... Like other peoples' friends and it, it just happens." (Paul; 97)

2.3.5.2. Relationships

Marie was the only participant who reported being in a relationship. Both Paul and James expressed a desire for a partner in the future:

"I wanna be with a girl and er... who I really, really love. So I can hold her tight every night, and kiss her every night, and tell her how much she means to me." (Paul; 74)

James explored his ambivalence around wanting a relationship; although he liked the idea of having a partner, he was aware of the lifestyle changes he would have to make to facilitate this:

"I like the idea of having a partner, but there again I wouldn't want to be committed to a long-term relationship. Er, I like the idea of getting married, but it means me having to change my entire lifestyle, my entire culture, my way of life. Even my habits at home, um... I would have to be more accommodating, more flexible, I'd have to be able to change, and I find those changes, um... it's like if I've been living my, I've, I've been living alone for so long now... Although there are couples that do live two separate lives....I'd be quite happy with that." (James; 401)

2.4. Discussion

2.4.1. Summary

The results of this research indicate that friendship is valued highly by the participants of this study, a small group of adults with AS/HFA. The participants identified friends from a range of sources, and demonstrated the ability to maintain friendships across the lifespan. They had clear ideas about what friendship meant to them, why they were drawn to particular people, and what function friendship served for them. Many participants were also aware of the differences between themselves and others, and the various barriers to initiating and maintaining friendships; they also described experiences of rejection and loss. Desires for the future were expressed, including increasing their number of friends and developing intimate relationships.

2.4.2. Findings in relation to existing literature

Müller et al. (2008) reported that their participants longed for social connectedness and put considerable energy into developing greater social understanding and self-awareness. This combined with the current study contradicts some previous suggestions that friendships have limited value to individuals with AS/HFA (Baron-Cohen and Wheelwright, 2003), and that in adulthood many individuals live isolated lives with few meaningful friendships (Orsmond et al., 2004). The functions of friendship mentioned here were not dissimilar to those found within the general population (Powers et al., 2009), for example, one participant described friends as

helping to counterbalance negative thinking and depression. Shared interests were highlighted as an important feature of friendship, in line with Daniel and Billingsley's (2010) findings.

The significance of adolescence was mentioned, and the changing role of friendship. Church et al. (2000) observed that children with AS seemed to learn more effective social skills and establish at least one friendship by the time they reached high school, although this was also a time of increased anxiety, perhaps as awareness of their difference became more apparent. A qualitative study by Carrington et al. (2003) examined the perceptions of adolescents with AS of friendship. Participants struggled to describe friendship and what it meant for them, and the authors concluded that they did not generally understand the nature and reciprocity of friendship. The participants in the current study seemed to have a better understanding of what constituted friendship; several demonstrated considerable reflection on their adolescent years, and one participant described conscious efforts to improve his self-awareness in order to function better in his social world. This fits with previous findings that theory of mind and self-awareness improve by adulthood in individuals with AS/HFA (Frith and Happé, 1999), perhaps as a result of increasing awareness during adolescence of the importance of these qualities to interact effectively with people, and deliberate attempts to learn these skills.

Four of the participants did not receive their diagnosis until adulthood. Recent qualitative papers have looked at the experience of receiving a diagnosis in young people (Huws and Jones, 2008) and in adults (Punshon et al., 2009). Many individuals

diagnosed later have been aware of being different throughout their life, and find that diagnosis provides a useful framework to understand their present and past difficulties (Punshon et al., 2009). Several participants confirmed this in the current study, describing searching for answers and a better sense of understanding post diagnosis. In the context of the many incidences of bullying and teasing described by participants, providing early diagnosis and support to individuals with AS/HFA and public education to minimise stigma is a priority.

Discussion of struggles and barriers participants experienced initiating and maintaining friendships is common (e.g., Sperry and Mesibov, 2005). These fit with the range of social deficits associated with diagnostic criteria for AS/HFA (APA, 1994), and documented linguistic difficulties (Landa, 2000). Participants seemed to have a good awareness of their AS/HFA and the difficulties it causes with social interactions, which is also widely documented by first person accounts (e.g., Lawson, 2006).

Social networking sites such as Facebook were mentioned by a number of the participants as a way of making contact and keeping in touch. Internet relationships were also highlighted as important to adults with AS/HFA in Müller et al.'s (2008) qualitative study. Although there is currently no ASD-related research, these sites may be particularly appealing and used more regularly by individuals with shy personalities (Orr et al., 2009). Therefore they may have relevance to the ASD population who can find direct communication with other people anxiety provoking and stressful.

2.4.3. Limitations

As with most qualitative research, the small sample size used in this study makes the results difficult to generalise to the wider population of adults with AS/HFA.

Purposive homogenous sampling was used for this study, in keeping with many qualitative research projects (Smith et al, 2009). All participants were connected with a particular voluntary organisation who provide social and employment support to people with AS/HFA in a large urban area. It could be argued that the participants were motivated individuals with experiences of friendship they were prepared to discuss. They may not be representative of the wider population of adults with AS/HFA, many of whom may not access statutory or voluntary services, and may be considerably more isolated.

By nature, IPA involves a degree of subjectivity on the part of the researcher (Smith et al., 2009). As stated earlier, the primary researcher was interested in looking at positive experiences of friendship. Whilst every attempt was made to get a full picture of friendship according to each participant, it is possible that positive experiences were picked up on more readily and given more weight during the analysis. There has been much debate about reliability and validity with qualitative research (Golafshani, 2003), and triangulation was used in order to minimise bias, involving the checking of sections of coded transcript by another researcher. Previous research has focused more on the social challenges and isolations experienced by adults with AS/HFA (e.g., Müller et al., 2008), and although elements of these

struggles were picked up during the current study, a range of more optimistic views of friendship were also highlighted.

2.4.4. Clinical implications

The findings from this study suggest that individuals with AS/HFA may place value on friendships, and friendship is thought to impact positively on factors such as depression and cardiovascular activity (Powers et al., 2009, Holt-Lunstad et al., 2007). Interventions by statutory and voluntary services should therefore focus on the facilitation of friendships, providing specialist social skills support where requested. Support to use social networking websites may also be of value for maintaining friendships when the anxiety of face-to-face contact is affecting social interactions; with time this may increase the sense of connectedness for individuals with AS/HFA. Early recognition and diagnosis of AS/HFA is important in order to help individuals understand the context of their social difficulties, and public education may help to reduce the stigma associated with ASD.

2.4.5. Areas for future research

The current study incorporates only one perspective on the experience of friendship; it may be useful to carry out a study incorporating multiple perspectives, such as those of named friends. This approach would add to the validity and reliability of findings from qualitative research (Golafshani, 2003).

There was only one female participant in the study, in keeping with the gender ratio of AS/HFA (Volkmar et al, 1993). Gender differences in friendships within the general population have been identified, with men typically having more instrumental friendships, based on the sharing of activities, and women typically having more expressive friendships, based on the sharing of emotions (Dwyer, 2000, Baron-Cohen and Wheelwright, 2003). Future research using larger sample sizes could examine whether these differences also apply to individuals with AS/HFA.

Much research has focused on improving the social skills of children with ASD, however as many individuals with AS/HFA are not diagnosed until adulthood (Punshon et al., 2009) it is important for future research to focus on interventions aimed at this age group. Peer support groups have been shown to be useful and valued by adolescents with AS (Weidle et al., 2006) and social cognition and interaction training groups have shown initial promise in adults with HFA (Turner-Brown et al., 2008). However, large-scale evaluations of group programmes would significantly add to the research base.

2.5. References

Allen G (1996) *Kinship and friendship in modern Britain*. Oxford: Oxford University Press.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington, DC: American Psychiatric Association.

Baron-Cohen S (2000) Is Asperger syndrome/high-functioning autism necessarily a disability? *Development and Psychopathology* 12: 489-500.

Baron-Cohen S and Wheelwright S (2003) The Friendship Questionnaire: An investigation of adults with Asperger Syndrome or High Functioning Autism, and normal sex differences. *Journal of Autism and Developmental Disorders* 33: 509-518.

Bauminger N and Kasari C (2000) Loneliness and friendship in high-functioning children with autism. *Child Development* 71(2): 447-456.

Boomsma A, Van Lang NDJ, De Jonge MV, De Bildt AA, Van Engeland H and Minderaa RB (2008) A new symptom model for autism cross-validated in an independent sample. *Journal of Child Psychology and Psychiatry* 49(8): 809-816.

Carrington S, Templeton E and Papinczak T (2003) Adolescents with Asperger syndrome and perceptions of friendship. *Focus on Autism and Other Developmental Disabilities* 18(4): 211-218.

Church C, Alisanski S and Amanullah S (2000) The social, behavioral and academic experiences of children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities* 15(1): 12-20.

- Daniel LS and Billingsley B (2010) What boys with an autism spectrum disorder say about establishing and maintaining friendships. *Focus on Autism and Other Developmental Disabilities* 25(4): 220-229.
- Demir M and Weitekamp LA (2007) I am so happy cause today I found my friend: Friendship and personality as predictors of happiness. *Journal of Happiness Studies* 8: 181-211.
- Dwyer D (2000) *Interpersonal relationships*. London: Routledge.
- Frith U (2003) *Autism: Explaining the enigma (2nd Ed.)*. Oxford: Blackwell Publishing.
- Frith U and Happé F (1999) Theory of mind and self-consciousness: What is it like to be autistic? *Mind and Language* 14(1): 1-22.
- Ghaziuddin M (2010) Brief report: Should the DSM V drop Asperger syndrome? *Journal of Autism and Developmental Disorders* 40: 1146-1148.
- Golafshani N (2003) Understanding reliability and validity in qualitative research. *The Qualitative Report* 8(4): 597-607.
- Holt-Lunstad J, Uchino BN, Smith TW and Hicks A (2007) On the importance of relationship quality: the impact of ambivalence in friendships on cardiovascular functioning. *Annals of Behavioral Medicine* 33(3): 278-290.
- Howard B, Cohn E and Orsmond GI (2006) Understanding and negotiating friendships: perspectives from an adolescent with Asperger syndrome. *Autism* 10(6): 619-627.
- Howlin P (1997) *Autism: Preparing for adulthood*. London: Routledge.

- Howlin P (2000) Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism* 4(1): 63-83.
- Huws JC and Jones RSP (2008) Diagnosis, disclosure, and having autism. An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability* 33(10): 99-107.
- Jenness-Coussens M, Magill-Evans J and Koning C (2006) The quality of life of young men with Asperger syndrome: A brief report. *Autism* 10: 403-414.
- Klin, A and Volkmar FR (1997) Asperger's syndrome. In: Cohen DJ and Volkmar FR (eds) *Handbook of autism and pervasive developmental disorders*. New York: John Wiley & Sons, 94-122.
- Koning C and Magill-Evans J (2001) Social and language skills in adolescent boys with Asperger syndrome. *Autism* 5 (1): 23-36.
- Kutnick P and Kington A (2005) Children's friendships and learning in school: Cognitive enhancement through social interaction? *British Journal of Educational Psychology* 75(4): 521-538.
- Ladd GW, Kochenderfer BJ and Coleman CC (1996) Friendship quality as a predictor of young children's early school adjustment. *Child Development* 67: 1103-1118.
- Landa R (2000) Social language use in Asperger syndrome and high-functioning autism. In: Klin A, Volkmar FR and Sparrow SS (eds) *Asperger syndrome*. London: Guilford Press, 125-158.
- Lawson W (2006) *Friendships: The Aspie way*. London: Jessica Kingsley Publishers.

Müller E, Schuler A and Yates GB (2008) Social challenges and supports from the perspective of individuals with Aspergers syndrome and other autism spectrum disabilities. *Autism* 12(2): 173-190.

Orr ES, Sisic M, Ross C, Simmering MG, Arseneault JM and Orr RR (2009) The influence of shyness on the use of facebook in an undergraduate sample. *Cyberpsychology and Behaviour* 12(3): 337-340.

Orsmond GI, Kraus MW and Seltzer MM (2004) Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders* 34(3): 245-265.

Powers A, Ressler KJ and Bradley RG (2009) The protective role of friendship on the effects of childhood abuse and depression. *Depression and Anxiety* 26: 46-53.

Punshon C, Skirrow P and Murphy G (2009) The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism* 13(3): 265-283.

Smith JA, Flowers P and Larkin M (2009) *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.

Sperry LA and Mesibov GB (2005) Perceptions of social challenges of adults with autism spectrum disorder. *Autism* 9(4): 362-376.

Turner-Brown LM, Perry TD, Dichter GS, Bodfish JW and Penn DL (2008) Brief report: Feasibility of social cognition and interaction training for adults with high functioning autism. *Journal of Autism and Developmental Disorders* 38: 1777-1784.

Volkmar FR, Klin A and Pauls D (1998) Nosological and genetic aspects of Asperger syndrome. *Journal of Autism and Developmental Disorders* 28(5): 457-463.

Weidle B, Bolme B and Hoeyland AL (2006) Are peer support groups for adolescents with Asperger's syndrome helpful? *Clinical Child Psychology and Psychiatry* 11(1): 45-62.

Whitehouse AJO, Durkin K, Jaquet E and Ziatas K (2009) Friendship, loneliness and depression in adolescents with Asperger's Syndrome. *Journal of Adolescence* 32: 309-322.

CHAPTER THREE

Seeing the wood for the trees: Reflections on the process of qualitative research involving participants with high functioning autism

Word count: 3028 (excluding references and footnotes)

3.1. Introduction

This paper includes some personal reflections on the process of conducting qualitative research with individuals with Asperger syndrome or high functioning autism. These thoughts and ideas were developed through research supervision sessions and the use of a reflective journal throughout my thesis; it is therefore written in the first person to reflect the personal nature of these ideas. The paper will consider experiences of conducting qualitative interviews and the relevance to this population, the significance of friendship, and whether high functioning autism should be viewed as a disability or difference.

3.2. Why isn't more qualitative research done with people on the autism spectrum?

Whilst trawling through the literature relevant to my thesis topic, it became apparent that much of the research does not directly involve individuals with autism¹¹. Many studies investigate the perspective of relatives or carers, and those that do involve individuals with autism directly often use questionnaires rather than one-to-one interviews. My thesis looked at experiences of friendship, and involved qualitative interviews of individuals with high functioning autism (HFA) and Asperger syndrome (AS). These individuals are generally verbally able with an average or high IQ, and as I was looking at experiences of social relationships, they seemed the best placed people to provide information. With other populations, researchers would not hesitate to do in-depth research directly with the individuals involved. So what is different about autism?

¹¹ Although 'autism spectrum disorders' or 'autism spectrum conditions' are commonly used terminology within the literature, I have chosen to use 'autism' to avoid using the label of disorder or condition. These terms are discussed further in section 3.5: Disability or difference?

3.3. The research process

Although I willingly chose to do a qualitative study and was keen to hear the perspectives of individuals with autism, I cannot pretend that the research was always a comfortable experience. In the early stages whilst trying to link in with existing support groups to use for recruitment, I was invited at the last minute by a contact to a local group meeting. However, the group members had not been informed that I would be attending, and made it clear that me turning up out the blue was quite unsettling for them. In hindsight, I should have had the common sense to ensure plenty of notice was given, however in my eagerness to get participants I didn't give it a second thought. Following that experience, I was careful to provide plenty of notice for contact with potential participants, and arrange interviews in locations familiar to them in order to minimise anxiety.

The interviews themselves also presented challenges. At times there were awkward silences, linguistic misunderstandings, and feelings of general discomfort. I had several moments of inner frustration when I realised participants were talking very tangentially on topics unrelated to my thesis, which I knew I would be unable to use. Despite trying to guide the conversation in the right direction, participants didn't always pick up on my gentle nonverbal cues or even quite direct verbal prompts to keep on topic. This is in keeping with difficulties people with autism have in recognising the subtleties of communication, and was a topic of conversation in itself for some of my participants. Indeed one participant spoke at length about his observation that people can talk too much on topics not of interest to the other

person, including himself, however he seemed unable to recognise it happening within the room.

Another participant gave me a hug at the end of the interview, which felt inappropriate to the relative formality of the situation. He had however enjoyed talking about his experiences, and I reasoned that giving me a hug was an expression of gratitude and his way of getting closure. After all, opening up to a complete stranger who you will never see again is a strange enough situation to encounter, without the added complications of communication difficulties associated with autism. My final participant turned the conversation around to me mid-interview, by directly asked why I had chosen my research topic. I felt very exposed, outside my comfort zone of carrying out interviews (and therapeutic interventions during my clinical placements) which are almost exclusively focused on the other person in the room. I also felt pressured to give a satisfactory and unambiguous response, so that he could go away from the interview feeling valued and respected by me as a researcher.

My experiences as a trainee clinical psychologist have prepared me well for sitting in a room with someone and tolerating a level of discomfort. I like to think that I am quite skilled at putting people quickly at ease, and judging what level of conversation will be appropriate for the situation. However, I couldn't help feeling deskilled at times during the interviews, and like I wasn't quite connecting with participants. As a trained therapist I have been able to reflect on these experiences and integrate my knowledge of the subtle social difficulties associated with autism. However, many researchers do not come from a clinical background, and may feel less equipped to

'sit with' uncomfortable experiences. They may lack adequate training and confidence to make the best of interview situations where participants are under or over talkative; this is of course not an experience confined to interviewing people with autism, however the autism may increase the likelihood of unexpected challenges in the interview process. This may go part of the way towards explaining why qualitative interviews with individuals with autism are not regularly used as a research methodology. Instead researchers may choose the 'easier option' of asking the opinions of carers and relatives, or using questionnaires which do not require the intensity of one-to-one research interviews.

3.4. The relevance of qualitative methodology

Despite being infrequently used with this population, qualitative methodology has much to teach us about the experiences of people with autism. The aim of Interpretative Phenomenological Analysis (IPA) is to understand peoples' experiences and the sense they make of them (see Smith, Flowers and Larkin, 2009). The focus is on how the individual has experienced the topic of study, in this case friendship, allowing for the exploration of personal perspectives without the need to group data into predefined categories. Of course this requires the participants of such studies to be able to express themselves sufficiently in a way that can be understood by the researcher conducting the interviews and analysis. Considering the whole spectrum of autism, people with HFA or AS therefore seem particularly suited to taking part in qualitative research as their verbal ability is usually strong.

There is however an argument that people with HFA have a restricted ability to reflect on their inner world. Frith and Happé (1999) discussed the research around

theory of mind, and the indication that the ability to self-reflect is also impaired in individuals with autism. People with HFA can often pass theory of mind tests by the time they reach adulthood but make slip-ups such as not understanding sarcasm, indicating a different brain process may be involved to that used by people without HFA. They also reported a study which sampled the inner experiences of three individuals with AS (Hurlburt, Happé and Frith, 2004), and concluded that inner experiences are typically visual images, and don't involve the reporting of feelings or curiosity about others' experiences. Frith and Happé (1999) also claim that the many autobiographical accounts of people with HFA demonstrate little awareness of other peoples' perceptions, or concern about the impression they may make. They argue that whilst these accounts are rich and varied, they may simply reflect the reconstruction of childhood memories incorporating other peoples' narratives.

This strikes me as a negative and unhelpful way of summarising this vast and significant body of literature. The popularity of such personal accounts is testament to the value and utility of reading about these experiences, both to people with autism and those supporting them, including families and professionals. These accounts serve to inform and normalise, and are more accessible to the general public than the volume of scientific literature available. In keeping with the phenomenological position of IPA, my belief is that the experience of the individual is valid and of interest, regardless of whether it conforms to societal expectations of the nature and depth of self-awareness and reflection.

3.5. The significance of friendship

There were two points of interest that led me to decide on my research topic of friendship in adults with HFA or AS. Firstly, the majority of research into autism focuses on children, at a time where individuals receive considerably more personal and professional support and are still growing and developing. Adulthood however usually constitutes by far the biggest proportion of people's lives, and I was intrigued to know what happened to individuals when the structured environments of school and college were removed. Families may maintain a close involvement in individuals' lives, however there is often a move to increasing independence and autonomy.

Secondly, friendships have played an increasingly important role in my own life, and are something I have given considerable thought to over recent years, particularly when reflecting on my personal development as part of my clinical psychology training. Certain friendships have been time-limited but powerful, leaving a significant impact on my personality and well-being. Other friends have been a consistent presence since childhood but have played a more prominent role during particular periods or times of transition. These many and varied forms of friendship have been the subject of many discussions and reflections with my friends, partners, family and other professionals.

In my adult life, partners have provided particularly close friendships. I have always maintained friendships outside of relationships, and see these as fulfilling different desires and needs to a partner. However, I have also observed many couples losing interest in outside friendships as their relationships grow closer, and have reflected

that perhaps their desires and needs for friendship are being fulfilled entirely by their partners.

As adults with autism are less likely to be in a long-term relationship, friendships seem particularly important for providing social experiences that might otherwise be fulfilled by a partner. Although some of my participants expressed a desire for intimate relationships, others anticipated the difficulties this might present and placed a lower value on this. Instead friendships seemed to fulfil some of the roles partners otherwise might. Indeed one participant talked about the role of friendship in supporting the transition into adulthood, separating from the family and establishing a life outside of that unit. This idea was something that resonated with me, and I found myself thinking about this conversation for some time after the interview.

During the process of carrying out the interviews, I often gave thought to how I would answer the questions if I was taking part in a similar study. Although I could easily identify who my closest friends were, I found it difficult to put into words exactly what it was about those relationships that made them 'work', and why others didn't. I could think of times when I had felt upset or hurt by a friend, but again it was difficult to articulate the details of ruptures and how exactly they had been repaired, or not. Friendship feels so instinctual that it is hard to break it down and explain the qualities and components.

In contrast, the participants very eloquently described the positive qualities of friendship and exactly what constitutes a friend. They were also able to talk at length about the barriers to establishing and maintaining friendships, including their own

personal qualities that make being friends with them awkward or difficult. One participant had given considerable thought to these issues during counselling prior to his diagnosis, and had undertaken a long and difficult journey towards self-awareness and understanding. This level of detail and self-reflecting both surprised and impressed me, and did not fit my preconceived ideas about people with autism. It also did not fit well with the argument put forward by Frith and Happé (1999) about inner experiences being primarily visual and devoid of feelings.

Williams (2004) discusses the idea that people with HFA do not have difficulty learning the rules of social engagement, it is applying them naturally and effortlessly that presents problems. This lack of 'social intuition' is the primary difference between typically developing people and those with HFA. Individuals may try to generalise from previous social experiences, and apply learnt rules rigidly at the expense of changing information; people around them may break the rules and introduce unpredictable emotions. Williams (2004) likens this to the difference between beginners and experts – beginners at any task rely more heavily on following explicit rules and strategies, whereas when you develop expertise this process becomes more flexible and happens outside conscious awareness. People with HFA are forced to intellectualise social interactions to get by and provide a certain level of predictability, however this may rarely lead to the expertise that makes interactions effortless and natural. This can lead to inflexibility and failure in social situations. The reasons behind this failure to develop social expertise in people with HFA are unclear, but could relate to difficulties engaging in mutual affective relationships in early childhood, due to features of autism such as problems with eye

contact and facial expression. See Williams (2004) for a summary of the research surrounding these ideas, which is beyond the scope of this paper.

During my research interviews and subsequent analysis, I often felt that participants were intellectualising what to other people are natural processes involving little conscious thought. Contrary to my prior preconception that people with HFA were socially awkward and oblivious to the intricacies of social interactions, I began to see that often they are painfully aware of these processes, but unable to use social instinct to join in effortlessly and flexibly.

3.6. Disability or difference?

To my knowledge I do not fulfil the criteria for a diagnosis of HFA or AS. However, during the process of carrying out my research interview, I found myself relating to many of the participants' descriptions and experiences of friendship. Many of the struggles and feelings of discomfort in social situations were experiences I could relate to at various points in my life, and I am certainly not alone within my wider social circle in having questioned aspects of relating to others.

This led me to consider the argument that HFA is not a 'condition' or a 'disability', but more of a spectrum upon which we could all be located. Baron-Cohen (2000) discusses the idea that 'impairments' associated with HFA and AS could be viewed instead as 'differences'. Being more immersed in the world of objects and more focused on detail rather than the whole is not necessarily a disadvantage, in fact in many fields such as engineering and mathematics, it can be advantageous. It is a societal expectation that people are sociable and interested in other people, however

being interested in objects rather than people does not make somebody a less valuable citizen. Baron-Cohen (2000) argues that if HFA were a disability, we would not expect to see the increase in prevalence that seems to be occurring internationally. Although this could be partially explained by an increase in recognition and diagnosis, it would be reasonable to expect that a disability affecting social skills would reduce mating opportunities and result in a reduced prevalence over time. If HFA is considered as simply a different cognitive style, certain qualities such as a focus on detail could be advantageous in terms of reproductive capacity, as individuals may be high earners and have a high IQ.

Indeed individuals with HFA do not necessarily view themselves as 'impaired'; Hurlbutt and Chalmers (2002) studied the thoughts and reflections of three individuals with HFA over a nine month period, and found that they identified with a unique culture and had no desire to be 'neurotypicals' (a term widely used for people without autism). They were happy to be considered experts on the topic of autism, and provide consultation on related issues if required. It is clear that HFA is not necessarily viewed by those individuals diagnosed with it as a true disability, and indeed many people are proud of their differences and unique qualities.

Despite this, the terms 'disorder' and 'condition' are still widely used within the literature, and the existence of diagnostic criteria within the ICD-10 (WHO, 1992) and DSM-IV (APA, 1999) means that a medical view of the autism spectrum persists. There is no medical test available to provide a definitive diagnosis, so instead diagnosis is made on the basis of professionals' assessment of the person's behaviour. This involves considerable subjectivity, and there are endless shades of

grey when interpreting the presence or absence of particular features and their severity (Molloy and Vasil, 2004). Although having a label can be helpful to some people, and undoubtedly some of the participants in this study had found it a useful framework to understand their difficulties, medical labels can be very difficult to remove once given, and reinforce the idea that autism is a disability rather than a difference.

3.7. Conclusion

The debate around whether HFA is a true disability is beyond the scope of this paper (see O'Neil, 2008 for a recent summary), and clearly individuals who are not at the high-functioning end of the autism spectrum have additional difficulties which both they and their families experience as problematic. However, it is widely accepted that people with HFA typically have an excellent eye for detail. Although 'not being able to see the wood for the trees' can result in various difficulties with social engagement and everyday life tasks, it has been argued that focusing on detail is very advantageous in certain careers and other aspects of life. The participants in my study were able to describe eloquently the detail of friendships which others without HFA may struggle to articulate, as the process of social engagement often happens outside conscious awareness.

My research has demonstrated that people with HFA are able to initiate and maintain friendships, which they value highly and are thoughtful about. By focusing on the elements and intricacies of these relationships, they are able to shed light on the usually effortless process of maintaining friendships in the wider population. Autism or no autism, friendships can be important and influential relationships across our

lifespan, and we could all learn some valuable lessons from listening to the experiences of those more aware of the detail.

3.8. References

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. Washington, DC: American Psychiatric Association.

Baron-Cohen, S (2000) Is Asperger syndrome/high-functioning autism necessarily a disability? *Development and Psychopathology*, 12, 489-500.

Frith, U and Happé, F (1999) Theory of mind and self-consciousness: what is it like to be autistic? *Mind and Language*, 14 (1), 1-22.

Hurlbutt, K and Chalmers, L (2002) Adults with autism speak out: perceptions of their life experiences, *Focus on Autism and Other Development Disabilities*, 17 (2), 103-111.

Hurlburt, RT, Happé, F and Frith, U (1994) Sampling the form of inner experience in three adults with Asperger syndrome, *Psychological Medicine*, 24, 385-395.

Molloy, H and Vasil, L (2004) *Asperger syndrome, adolescence, and identity: looking beyond the label*, London: Jessica Kingsley Publishers.

O'Neil, S (2008) The meaning of autism: beyond disorder, *Disability and Society*, 23 (7), 787-799.

Smith, JA, Flowers, P and Larkin, M (2009) *Interpretative phenomenological analysis: theory, method and research*, London: Sage.

Williams, E (2004) Who really needs a 'theory' of mind? An interpretative phenomenological analysis of the autobiographical writings of ten high-functioning

individuals with an autism spectrum disorder, *Theory and Psychology*, 14 (5), 704-724.

World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*, Geneva: WHO.

A. Ethical approval letter

**REGISTRY RESEARCH UNIT
ETHICS REVIEW FEEDBACK FORM**
(Please return to Registry Research Unit within 10 working days)

Name of applicant and Faculty/School: Sophie Chappell, HLS

Research project title: An exploration of friendship in adults with Asperger's Syndrome or High Functioning Autism

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

It is obvious that Sophie has recognised the various ethical issues involved in the study and has addressed them appropriately. It is realised that some participants may experience some emotional distress, and Sophie has responded to this in a carefully considered way. The ethics of recruitment of participants, confidentiality, security and retention of data has been taken into account.

2. Evaluation of the participant information sheet and consent form:

The participant information sheet is clear and informative (spelling mistake in section "Do people have to take part? - "my by email"). Might state when the project will be finished, that is, a date after which the data will be destroyed.

The consent form is clear and concise.

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

✓

Approved - no conditions attached

Conditional upon the following – please use additional sheets if necessary

Rejected for the following reason(s) – please use additional sheets if necessary

Further advice/notes - please use additional sheets if necessary

Name and signature of reviewer: Katherine Simons

Date: 14th March 2010

B. Information for participants

Yes. Only I will have access to the audio-tapes and the transcriptions of the interviews, which will be kept in a locked cabinet. The tapes and transcriptions will be given an identification code rather than being labelled by name. They will be destroyed by May 2012. When the findings are written up, all quotes will be identified by the code rather than your name, and any other identifying details will be removed.

What will happen to the results of the research study?

The findings of the study will be written up and presented as part of my Clinical Psychology doctoral thesis. The paper may also be submitted to the journal 'Autism', and presented at a National Autistic Society conference. No names or identifying details will be included. If you wish to receive a written summary of the main findings from the study, please tick the box on the Consent Form. Unfortunately feedback on your particular interview will not be available.

Who is organising and funding the research?

The research is organised by Sophie Chappell, who is a Trainee Clinical Psychologist at Coventry University. This project is funded by the University. ***** have kindly agreed to help with the recruitment of participants.

Who has reviewed the study?

This study has been through the University Peer Review process and been approved by the Chair of the University Applied Research Committee.

Contact for further information:

Sophie Chappell (main researcher)

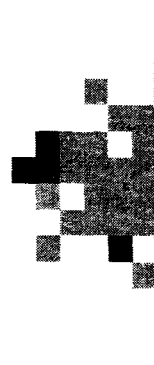
***** (address)

Email: *****



Sophie Chappell

Tel. *****



THE UNIVERSITY OF
WARWICK



Research Information Leaflet

A study into the experiences of friendship in adults with Asperger Syndrome (AS) or High Functioning Autism (HFA)

This leaflet gives you information on the study I am undertaking as part of my research for my Doctorate in Clinical Psychology. The leaflet describes the purpose of the study and what taking part in the study will involve. If you have any additional questions please contact me using the details at the end of the leaflet

What is the purpose of the study?

The aim of the study is to find out about experiences of friendship in adults who have a diagnosis of either Asperger Syndrome (AS) or High Functioning Autism (HFA).

Why have you been approached?

I am planning to recruit a small number of adults who have a diagnosis of either AS or HFA. ***** have kindly agreed to support the study.

Do people have to take part?

No, participation is entirely voluntary. If you change your mind about taking part in the study you can withdraw at any point during the interview and at any time in the two weeks following that session. You can withdraw by contacting me by email or telephone (details at the end of this sheet). If you decide to withdraw all of your data will be destroyed and will not be used in the study. There are no consequences to deciding that you no longer wish to participate in the study.

What will happen if you decide to take part in the study?

You will be asked to come to a venue, chosen by you, for a one-to-one interview with me. This will last approximately one hour. During the conversation you will be asked questions about your experiences of friendship throughout your life. This will be tape-recorded, and you are free to take a break at any point.

What are the possible disadvantages and risks of taking part in the study?

You may find it upsetting to talk about some of your past and present experiences of friendship. You are free not to answer any of the questions you might find difficult, or decide not to take part in the research even after the interview has finished.

What are the possible advantages of taking part?

Everybody who takes part in this study will be entered into a prize draw for a £20 voucher for high street shops. The winning name will be drawn after the last interview has taken place, and the winner will be informed by post. The study gives you the opportunity to talk about your experiences of friendship, including the things you enjoy and the difficulties you have encountered. This information will be helpful to the general public, professionals and people with AS, particularly when looking at ways to provide you with the best support.

**What if something goes wrong or if you are not happy with some part of the process of taking part?**

If you change your mind about taking part in the study you can withdraw at any point during the interview and at any time in the two weeks following that session by contacting me using the email address or telephone number stated below. If you decide to withdraw all of your data will be destroyed and will not be used in the study. However your name will still be entered into the prize draw. If you feel distressed after taking part in the study, and wish to talk to someone other than family or friends, you can contact:

Dr Gavin Farrell - Chartered Clinical Psychologist. Tel. *****

If you wish to complain about any part of the research study, please contact Dr Gavin Farrell (details above).

Will taking part in this study be kept confidential?

Your contact details

If you think that you would like to take part in the research study described in the Research Information Leaflet, please write your contact details in the space below:

Name.....	
Telephone number:.....	
Address:.....	
.....	
.....	
.....	
How would you prefer to be contacted? (please tick box):	
Telephone <input type="checkbox"/>	Post <input type="checkbox"/>
Where would you prefer to come for your interview? (please tick box)	
<i>**Location one**</i>	<input type="checkbox"/>
<i>**Location two**</i>	<input type="checkbox"/>
<i>**Location three**</i>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

****Please put this piece of paper in the stamped address envelope provided and post to the researcher****

Sophie Chappell (the main researcher) will contact you over the next few weeks to arrange an interview. You are free to change your mind about taking part in the research even after sending your contact details. Please tell Sophie Chappell when she contacts you, or use her contact details on the Research Information Leaflet, and she will not telephone or write to you again. Thank you for helping with this research project.

C. Interview forms

Consent Form

Study into the experiences of friendship in adults with Asperger Syndrome or High Functioning Autism, as detailed in the Information Leaflet.

Please tick

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving a reason.

☐

3. I understand that all the information I provide will be treated in confidence.

☐

4. I understand that I also have the right to change my mind about participating in the study for two weeks after my interview has taken place, by contacting the researcher.

☐

5. I agree to be tape-recorded as part of the research project.

☐

6. I agree to take part in the research project.

☐

7. I would like to receive a summary of the research findings by post.
(this will be posted to the address you initially provided to be contacted at)

☐

Name of participant:

Signature of participant:

Date:

Name of Researcher:.....

Signature of researcher:

Date:.....

Participant no:.....

(Headed paper)

Thank you for agreeing to take part in this research project. Before the interview starts, please could you answer the questions below, to provide us with some more information about you:

1) Are you:

Male ☐

Female ☐

2) How old are you?

.....

3) Have you received a diagnosis of:

Asperger Syndrome ☐

High Functioning Autism ☐

Other? ☐

4) How old were you when you received a diagnosis?

..... years old

5) What is your ethnicity?

.....

6) What is your marital status?

Single ☐

Cohabiting ☐

Married/civil partnership ☐

Separated ☐

Divorced ☐

Widowed ☐

Other ☐

.....

7) What is your employment status?

Employed - paid ☐

Employed - voluntary ☐

Student ☐

Self-employed ☐

Receiving benefits ☐

Other ☐

.....

8) How would you describe your living situation?

Living alone ☐

Living with partner/spouse ☐

Living with family ☐

Living with friends ☐

Supported living ☐

Living in a residential home ☐

Other ☐

.....

D. Interview schedule

Interview Schedule *Version 3 – 20.08.10*

1. (OPTIONAL) Tell me about the support group you attend
 - How long have you been going?
 - What sort of people go there?
2. Are there any people in your life at the moment who you would describe as a friend? IF NO – Q6
 - Who are your closest friends? Genders, ages, ASD?
 - How did you meet them?
 - What sort of things do you do with them/shared interests?
 - How often do you see them?
 - How do you get in touch?
3. Are you happy with the friends that you currently have?
 - The amount of friends you have / people you're friends with
4. Did you have many friends when you were a child?
 - Did you get on well with people at school?
 - Did you have a best friend?
 - Are you still in contact with any of those friends now?
5. How do you find friendships now, compared to when you were younger?
6. ONLY IF NO FRIENDS – Why do you not have friends at the moment?
 - Would you like to have friends?
 - Are you happy with people in your life?
7. What do you think 'friendship' means?
8. What are/would be the benefits of friendship to you?
 - What do/would you like about them?
 - What do/would you get out of friendships?
9. Is there anything that you have found difficult about friendship?
10. Tell me about any fall-outs you have had with friends?
 - How did you make up?
11. If you wanted to make more friends, do you have any ideas about how you would do it?
 - Where would you look for friends?
 - What sort of people would you like to be friends with?

E. IPA analysis

The steps of Interpretative Phenomenological Analysis (IPA). Adapted from Smith et al. (2009).

Step	Description
Reading and re-reading	This involves becoming immersed in the data, by listening back to the interview and repeated reading of the transcript. Initial notes and observations can be made to capture first impressions.
Initial noting	This is the most detailed and time-consuming stage, involving the examination of semantic content and language use on an exploratory level. Comments can be descriptive (focusing on content), linguistic (focusing on specific language use by the participant) and conceptual (interrogative and interpretative).
Developing emergent themes	This step involves reducing the volume of detail whilst maintaining complexity, by mapping the interrelationships, connections and patterns between exploratory notes. The emergent themes reflect the participant's original words and thoughts in addition to interpretation.
Searching for connections across emergent themes	This involves the development of a charting or mapping of how the analyst thinks the themes fit together. This structure should encompass the most interesting and important aspects of the participant's account. Themes can be grouped according to factors such as frequency, context, and polarisation.
Moving to the next case	The previous steps are repeated with the next case, as far as possible treating each case on its own terms doing justice to its individuality.
Looking for patterns across cases	The final step involves identifying patterns across cases, often involving the reconfiguring and relabeling of themes and moving the analysis to a more theoretical level.

Section of coded transcript.
 Within the initial notes: descriptive comments describe content, *conceptual comments* are interpretative and interrogative.

Emergent themes	Transcript – George page 1 (I = interviewer, P = participant)	Initial notes (Descriptive, <i>conceptual</i>)
<p>Friend from college. Mixed gender friendships.</p> <p>Met friend through internet. Shared interests.</p> <p>Met friends through friends.</p> <p>Friends with neighbours.</p>	<p>I: So, the first question is if, erm... is there anyone in your life at the moment that you'd describe as a friend?</p> <p>P: Er... yes.</p> <p>I: Yeah? Could you tell me about them.</p> <p>P: OK, so... I know a... well, John and Claire I've known for quite a while, I was at college with John back in the early 90s so... I dunno, er... then... er... so I've got people like Craig, and his....his partner and their friends and...</p> <p>I: Yeah? So you mentioned one person was from college, how do you know the other people?</p> <p>P: Er... Craig I met through a....message board on the internet that er... that was about Wolverhampton football club, we were both identified we were from Birmingham. Turns out we were only living like three sort of streets away from each other, (<i>indistinguishable</i>), interesting you know, sort of thing so... and we've sort of, we have different views, but we sort of click, so like... we do talk about different things and... so... so yeah, so I met him, then through Jess, and then a lot of other people through them as well, so...</p> <p>I: Mmm.</p> <p>P:but, er... so yeah, and there's other friends as well, I mean... Nick and Sarah, who I... I lived in the flat about them in Wolverhampton for quite a few years, so we got a, a friendship developed there so.... so...</p> <p>I: So from various different places.</p> <p>P: It does, yeah.</p> <p>I: Mmm. And what do you like about friendship, what...what kind of things do you get out of it?</p>	<p>Friends for a while.</p> <p>Friends from college.</p> <p>Partners of friends. <i>Makes a connection with someone, tags onto people linked to them.</i></p> <p>Met through internet message board.</p> <p>Physical proximity.</p> <p>Different views to friend.</p> <p>Talk about lots of things.</p> <p>Met friends through friends.</p> <p><i>Not good at making connections with people?</i></p> <p>Friends with ex-neighbours.</p> <p>Friends with couple.</p>

Emergent themes	Transcript – George page 2 (I = interviewer, P = participant)	Initial notes (Descriptive, <i>conceptual</i>)
<p>Hard to define friendship.</p> <p>Chatting with friends.</p> <p>Shared activities.</p> <p>Enjoying company.</p> <p>Regular contact.</p> <p>Keep in touch via internet.</p> <p>Regular/structured activities.</p> <p>Flexibility of contact.</p>	<p>P: ... Mmm, that's a very broad, er... [long pause]... [sighs]...that's a... question.</p> <p>I: Mmm.</p> <p>P: ... I'm sure most people don't even think about that.</p> <p>I: Yeah.</p> <p>P: Er... well, you know, you sort of er... well it's just a sort of normal sort of human interaction, sort of... talking to them about things and that stuff, or you can go out and do things together, er... me and Craig sort of go out sort of er... few, do a few trips you know, to the football and things, and occasionally invites me round on a poker night and stuff like that, so it's just normal spend time with them or just enjoying their company.</p> <p>I: Yeah.</p> <p>P: Just... normal things really I would say.</p> <p>I: Yeah? And how often are you in touch with those people?</p> <p>P: Er... well depends er... I'm sort of in touch with Craig probably.... at least twice a week, mainly on line more than anything else. But then sort of meet up occasionally. Er, I tend to see John and Claire once every couple of weeks or so.</p> <p>I: Yeah.</p> <p>P: You know sort of, we've got a regular...me and John also tend to go to a pub quiz on the...</p> <p>I: Ah right.</p> <p>P: ... you know, Walsall on a fortnightly basis so, we sort of have regular sort of... sort of structure and things, but also occasionally I'll drop in, just have a chat and things. Just depends.</p>	<p>Hard to define friendship.</p> <p><i>Friendship is instinctual, not thought out.</i></p> <p><i>Normalising.</i></p> <p>Friendship is normal interaction. Talking with friends. Shared interests and activities. Enjoying company of friends. <i>Normalising to me/himself.</i></p> <p>Friendship is normal.</p> <p>Regular contact with friends. Keep in touch via internet. Occasional face-to-face contact. <i>Internet is easier way of keeping in touch.</i></p> <p>Regular shared activity.</p> <p>Regular structure to socialising. Flexible contact.</p>

Emergent themes	Transcript – George page 3 (I = interviewer, P = participant)	Initial notes (Descriptive, <i>conceptual</i>)
<p>Keeping in touch via telephone. Infrequent contact with friends. Worried about over-imposing. Need my own space.</p> <p>Judging level of contact is hard.</p> <p>Laid-back friend.</p> <p>Flexibility of contact.</p> <p>Friends have other priorities.</p>	<p>I: Yeah. So varied according to the person. P: Mmm. I: And you mentioned that you keep in touch with people online, so, are there any other ways that you keep in touch or is that one of the main ones? P: Er... occasionally through telephone, mobile phone, texting, er... not a great one for keeping up with... friendships though, you know sort of, occasional contact more than anything else. I: Yeah. Is there anything that you found, find difficult about friends and friendship? P: Yeah, I mean I don't want to, to sort of over-impose on people, and things and I try to... and sometimes I need my own space as well, so I like to bit of a gap from people, so... so sometimes it's hard to judge how much friends and... you know, it's just all that sort of judging thing really, so... I: Yeah. Judging things like...? P: ... Well, when people are happy to have you around, and when you're sort of trying to be a, you know, treading in onto something else, and stuff like that really, so... sort of varies. I: So judging what, what other people are thinking is difficult. P: Mmm. Well yeah. I mean... you know, er people like Craig are just sort of laid back to the point of horizontal, so... I: <i>[laughing]</i> P: ...you know, he doesn't... he'll literally go with the flow wherever it goes really, so he's not a bit one for planning or anything like that, so... Obviously John and Claire have a family and all that, those things, so there's only like so much time you can pop in for a cup of tea and things, and then sort of move on, so, but it really just sort of depends on where, where people are.</p>	<p>Keeping in touch via phone. Prefer occasional contact. <i>Finds it difficult to be close.</i></p> <p>Worried about over-imposing. Need my own space. Difficult to judge closeness. <i>Finds people hard to read.</i> Can't always tell if others want me there. <i>Probably errs on the side of caution.</i></p> <p>Friends are laid back.</p> <p>Friend is laid back. Friend isn't a planner. Friends have other priorities. <i>He doesn't have those things – jealousy?</i></p>

Table of one participant's results - Aaron

Subordinate theme 1	Subordinate theme 2 and illustrative quotes
Source of friends	<p>Mixed gender friendships <i>"The one whose female, she's um... er, I, I'd talk, you know, we, we can sort of talk about um, a lot of different things really and um... the other one, like I say, we hit it off straight away and because we were sort, doing like a creative based course um, we worked really well together. "</i></p> <p>School friends <i>"I suppose I had a best friend at school, you know, 'cause we shared similar interests, and er, I suppose again, they were more acquaintances than anything at school, because we didn't really live anywhere near each other so it was very difficult for us to meet up. "</i></p> <p>Met through group situation <i>"Er, I think in fairness when er, with the people I've made friends with and who I would consider my best friends, it was a case of we were put in groups together, and you, sort of like, really through talking to them more than anything."</i></p> <p>Friends from uni <i>"I met them both when I was at York uni."</i></p> <p>Friends since school <i>"Um, well one of my best friends, I've known him for ten years now, um... I um, well I say ten, it's really like, um, well eleven. Um, I met him when I was in my last year of school, um..."</i></p>
Level of friendship	<p>Acquaintances <i>"I um, I have a few friends um, some I would class as er, you know, best friends really I mean, I suppose but most I'd sort of describe as um, acquaintances more than anything."</i></p>

	<p>Best friend <i>"And um, another one of my, my friends um... well one of my best friends, well, I say one of 'em, it's two really."</i></p> <p>Happy with amount of friends <i>"I: Um, and are you happy with the amount of friends that you've got at the moment?"</i></p> <p><i>P: Yeah, I, I think so."</i></p>
Qualities of close friendship	<p>Openness <i>"And I suppose another thing is where you can have pretty open conversations about anything."</i></p> <p>Shared interests <i>"I think it's sort of where it's like, something where you can share, share your thoughts really with um other people. Um... you know, interests, as, as well."</i></p> <p>Strong connection <i>"We hit it off straight away and because we were sort, doing like a creative based course um, we worked really well together. We seemed to be thinking more or less the same thing and, you know, we seemed to just instinctively, you know, could tell what the other one was thinking really."</i></p> <p>Friends help me out with problems <i>"I think for me, friends are, they're probably like more the first people I would contact really if um, I felt I had a problem or if I wanted to invite them... anywhere, I, I think that for me is like the main difference, if I, if I needed to contact people they would be, er, the first ones who I would, you know, pick up the phone or, um, whatever really. "</i></p> <p>Sharing thoughts <i>"I think it's sort of where it's like, something where you can share, share your thoughts really with um other people. "</i></p> <p>Friendship is important <i>"I think so, yeah it's, I think it's fairly important, especially with the ones who I consider to be my best friends really."</i></p>

	<p>Closer than family <i>"We can tell each other things that we wouldn't normally tell to other people, you know, maybe including our parents."</i></p> <p>Give each other honest feedback <i>"If one of us is doing something that the other one doesn't like, they'll tell us and they'll know it's, it's nothing personal."</i></p> <p>Bounce ideas off each other <i>"With my one friend I mean, you know, we're both sort of creative people, and if I've got an idea for something I... I'll run it past him and I'll know I'm gonna get an honest answer, you know. If he says it's, it's a good idea, then it's a good idea."</i></p> <p>Honesty <i>"It's just er, a very good open relationship and it's also one where we can be honest with each other."</i></p> <p>Drinking with friends <i>"If he, if he comes down to, you know, Coventry then, you know, we'll go, we'll go out for a drink and er, you know, have a night out really."</i></p>
Keeping in touch	<p>Telephone to keep in touch <i>"Yeah mainly by phone yeah. I mean sometimes it's, you know, the odd text message is sent, but it is mainly by phone."</i></p> <p>Physical distance from friends <i>"Er, the one I've known for more than ten years, he's based in London 'cause he's a vet and um... er, the other two they're, they're based down in Cornwall, 'cause she lives there anyway, and the other guy he's in er, Hastings."</i></p> <p>Difficult to arrange meeting up <i>"Yeah, I mean sometimes he comes down as well, and you know, if I'm not working because I work behind a bar, so it, it's quite difficult you know, if he's around and, and I'm working, you know. "</i></p> <p>Infrequent contact with friends <i>"I: So how often are you in touch with those people now?"</i></p>

	<i>P: Admittedly not very often."</i>
Increasing self reflection	<p>Learnt from experience <i>"I mean, you get older, you, you... I suppose you become a bit more ring smart."</i></p> <p>Learnt from mistakes <i>"I think it's just, sort of like, making mistakes really more than anything."</i></p> <p>Self-discovery <i>"I suppose, when you're sort of sixteen, seventeen, eighteen, you're trying to find out a lot about yourself really, more than anything."</i></p> <p>Used to try hard to impress <i>"I think it's fair to say that when I was, you know, fourteen, fifteen I probably was trying a bit too hard, you know, to impress people who I wanted to be friends with."</i></p> <p>Reflecting on past <i>"I mean this was more the case... you know, when I was approaching my teenage years when you'd fall out with your friends over stupid things really, and... after a while you'd make up and then, I suppose it's only really now... you look back and think, why, why did I do that (laughing), you know, why did we fall out over that, it was just plain stupid really."</i></p> <p>Can't make friends with everyone <i>"It seemed to me that, you know, they um... you know, you put a whole group of people together, you know, there'll always be like the different factions of er, of friends really and, and they just went in their own direction really."</i></p> <p>Honesty led to rejection <i>"I'm not very open about it now...you know, some people say you know, you need to be more open, more honest, and that's fair enough. Well sorry, I've been open and honest and it's got me nowhere really..."</i></p>

	<p>Haven't handled changes well <i>"I suppose, when you're sort of sixteen, seventeen, eighteen, you're trying to find out a lot about yourself really, more than anything, and you come across er, different challenges, and maybe I, I didn't handle them as well as I could have done."</i></p> <p>Social awkwardness <i>"And because of that bubble I, I don't think I really knew how to conduct myself in public so, people probably thought of me as a bit of an odd nut or you know... um, just someone who they couldn't quite pin, pin down really."</i></p>
Difference	<p>Easy target for bullying <i>"I wasn't very well liked or, 'cause what it was, the other kids, they knew I was you know, different, and of course that made me the um, easy target really."</i></p> <p>Different to others <i>"I wasn't very well liked or, 'cause what it was, the other kids, they knew I was you know, different."</i></p> <p>Judged negatively for going to a special school <i>"The kids who I grew up with, you know, where, where I was living at the time, you know, that was it you know, they only needed to hear the word 'special needs', hear the words sorry, and that was it, you know. They wanted absolutely nothing to do with me at, at all so..."</i></p> <p>Self protection <i>"I suppose maybe it's survival instinct I mean, nowadays, I mean when people are talking in groups... I would practically ignore 'em really."</i></p> <p>People don't think I'm interesting <i>"And I, and I think... I wouldn't say I was being ignored, but it seems to be like, you know, er, the other people in the group have more to say and... and probably are deemed more interesting people I guess."</i></p> <p>People think I'm stupid <i>"Other people, if other, regular people made mistakes, it was like, 'oh it's OK, it's what you do', and when it was me, it was</i></p>

	<p>like, 'oh for God's sake'."</p> <p>Punished for mistakes more than others <i>"I did sort of feel when I, especially when I was younger that when I made a mistake, I was punished more for it because I was a 'spacca' and... all that, you know."</i></p> <p>Learnt to cope with difference <i>"I suppose... it doesn't really affect me, because as I've, I've got older I've found better ways of coping with it and dealing... with it."</i></p>
Experience of special school	<p>Didn't need to go to a special school <i>"I suppose it's one of these things that with me, that I could probably argue 'til I'm blue in the face and when, if I'm thinking oh you, whether or not I really needed to go to that school for the amount of time that I did, you know, to correct my problems."</i></p> <p>Special school was a bubble <i>"I think really, that comes down to when, when I was, when I was at school. It was a bit of a bubble... um, if you would, because our school teachers would be saying, you know, you know the world's like a rosy, you know, very rose tinted spectacles and, you know, everything would work out OK but, I was growing up on a run-down council estate and I was seeing exactly the opposite..."</i></p> <p>Special school didn't prepare me for the real world <i>"When I... left school at sixteen, it wasn't probably 'til a couple of years later that I realised, actually, it didn't prepare me for the outside world at all."</i></p> <p>Bullied due to AS <i>"I was often getting the, the taunt of like, you know, spastic, spacca... you know, thicko and er, and all the rest of it really. I don't know whether it was just, you know, ignorance or people just thinking, 'oh he's different, let, let's have him'."</i></p>

	<p>Few friends at school</p> <p><i>"I: So thinking back to when you were at school, did you have many friends then, when you were school age?"</i></p> <p><i>P: Um, not particularly no."</i></p>
Ruptures and repair	<p>Stubbornness</p> <p><i>"I suppose when you, you'm lads you've... you're too stubborn to admit you was wrong to begin with."</i></p> <p>Falling out</p> <p><i>"Plenty of fallings out, I mean, just difference of opinion."</i></p> <p>Apologising</p> <p><i>"I think it was sort of apologising first really."</i></p>
Meeting new friends	<p>Meeting new friends doesn't matter to me</p> <p><i>"I've got a bit older and I've, and I've learnt you know what, it doesn't really matter that much to me."</i></p> <p>Could meet friends through group</p> <p><i>"I think I'd probably look at um, joining groups that reflect my own interests more than anything."</i></p> <p>Find making friends hard</p> <p><i>"I've always found it difficult to make friends."</i></p> <p>Find talking to new people difficult</p> <p><i>"Sometimes I er, I can't um... sort of speak. I'm very much on the outside."</i></p> <p>Approaching new people is hard</p> <p><i>"I think what I find difficult about making friends is um, talking to people sort of straight away really, like approaching people. Um... I've always found that quite difficult."</i></p>

F. Instructions for authors

Manuscript Submission Guidelines: *Autism: The International Journal of Research and Practice*

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11. **Further information**

Autism provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

1. Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

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2. Article types

The Journal considers the following kinds of article for publication:

1. Research Reports, describing new experimental findings;
 - (a) *Full papers*
 - (b) *Short reports requiring rapid dissemination*

2. Review Articles. The Editors wish to encourage the following types of review, but request that authors contact them in advance:

- (a) *general reviews that provide a synthesis of an area of autism research;*
- (b) *critiques - focused and provocative reviews that are followed by a number of invited commentaries, with a concluding reply from the main author;*

3. Letters to the Editors. Readers' letters should address issues raised by published articles or should report significant new findings that merit rapid dissemination. The decision to publish is made by the Editors, in order to ensure a timely appearance in print.

4. Book Reviews. A list of up-to-date books for review is available from the Journal's Editorial Manager.

Full papers are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, references, tables, biographical statement, etc.). We are reluctant to burden our referees with very long manuscripts. Editors may ask authors to make certain cuts before sending the article out for review.

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3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Autism is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

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4. Journal contributor's publishing agreement

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5. Declaration of conflicting interests

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6. Other conventions

We would prefer to use the term 'people with autism' or 'people with autism spectrum disorders or conditions'. We would also prefer the term 'typically developing' rather than 'normal'.

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7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with "and" before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaa].

In some cases, research is not funded by a specific project grant, but rather from the block grant and other resources available to a university, college or other research institution. Where no specific funding has been provided for the research we ask that corresponding authors use the following sentence:

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Please include this information under a separate heading entitled "Funding" directly after any other Acknowledgements prior to your "Declaration of Conflicting Interests" (if applicable), any Notes and your References.

Important note: If you have any concerns that the provision of this information may compromise your anonymity dependent on the peer review policy of this journal outlined above, you can withhold this information until final accepted manuscript.

For more information on the guidance for Research Funders, Authors and Publishers, please visit: <http://www.rin.ac.uk/funders-acknowledgement>

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

9.2 Journal Style

Autism conforms to the SAGE house style. [Click here](#) to review guidelines on SAGE UK House Style

9.3 Reference Style

Autism operates a Sage Harvard reference style. [Click here](#) to review the guidelines on SAGE Harvard to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

9.4.1 Your Title, Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on [How to Help Readers Find Your Article Online](#).

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

If, together with your accepted article, you submit usable colour figures, these figures will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. If a charge applies you will be informed by your SAGE Production Editor. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

9.4.4 Guidelines for submitting supplemental files

This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's [Guidelines for Authors on Supplemental Files](#).

9.4.5 English Language Editing services

Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit <http://www.sagepub.co.uk/authors/journal/submission.sp> for further information.

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10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

10.2 E-Prints and Complimentary Copies

SAGE provides authors with access to a PDF of their final article. For further information please visit <http://www.sagepub.co.uk/authors/journal/reprint.sp>. We additionally provide the corresponding author with a complimentary copy of the print issue in which the article appears up to a maximum of 5 copies for onward supply by the corresponding author to co-authors.

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We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Autism* with SAGE.

10.4 OnlineFirst Publication

Autism benefits from OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [OnlineFirst Fact Sheet](#)

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

Katie Maras

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Good Autism Practice

Notes for contributors

Aims and content of the publication

1. The aim of the journal is to publish examples of good practice (or an analysis of the issues affecting practice) in working with, or supporting, individuals with an autistic spectrum disorder and their families, throughout their lives that is judged to be innovatory or helpful for others to know about. Papers should not previously have been published nor be under consideration elsewhere.
2. Each paper submitted will be refereed by at least one anonymous referee as well as by the editors. Papers will be put into house editorial style.
3. Each issue will aim to have around four or five papers of between 3,000 and 4,000 words, plus two or three papers between 1,000 and 2,000 words. Articles should be submitted to the word lengths indicated. There may be photographs, diagrams and tables.
4. The journal will also take reviews of books, videos, educational or in-service packages, computer programs and TV programmes related to practice. These will normally be commissioned by the editors, so voluntary reviews should be checked with the editors before submission.

Form in which papers should be submitted

5. Papers should be submitted as an electronic attachment but may also be submitted in paper form with the agreement of the editor.
6. Authors should provide two title pages. One should contain the names, affiliations, full mailing address plus telephone, fax, e-mail address of the author(s). The second title page should contain the title only. This is so the referee(s) will not be able to identify the author(s) when refereeing.
7. Please number all the pages except the title pages and include any acknowledgements, address for correspondence, main text, references and appendices.
8. Articles submitted for publication must be word-processed or typed in double spacing throughout (including all notes and references), on one side only of white A4 paper, with generous left- and right-hand margins. Pages should not be stapled. Titles and section headings should be clear and brief with a maximum of three orders of heading.
9. Lengthy quotations (exceeding 40 words) should be displayed and indented in the text. These are not to be encouraged. It is the author's responsibility to check all quotations for infringement of copyright and to obtain permission to use the quotation, where necessary. Permissions should be sent to the editor along with the article.

10. Tables and figures should have short, descriptive titles and be clearly numbered. All footnotes to tables and their source(s) should be typed below the tables. Column headings should clearly define the data presented.

Confidentiality

11. It is the responsibility of the author(s) to ensure that all who have contributed to the paper or the work presented are acknowledged and that they have given their permission for the article to be published.

References

12. The references should be listed alphabetically in full at the end of the paper, in the following style:

Johnston, P and Hatton, S (2003) *Conversations in autism: from insight to good practice*, Kidderminster: British Institute of Learning Disabilities.

Hobson, RP (1989) *Beyond cognition: a theory of autism*, in G Dawson (Ed) *Autism: nature, diagnosis and treatment*, New York: Guilford.

Sigman, MD, Kasari, C, Kwon, J and Yirmiya, N (1992) Responses to the negative emotions of others by autistic, mentally retarded and normal children, *Child Development*, 63 (3), 796–807.

In multi-authored articles, the names of authors should be given in the reference list.

13. Jargon or unnecessary technical language should be avoided. Wherever possible, use non-discriminatory language that places the person first (eg 'adults with autism' rather than 'autistic adults') and is not sexist (eg not assuming that all children are boys, all teachers or support staff, women) nor racist.
14. Initials should be avoided, except for terms in common use. Abbreviations that are common enough to be in the dictionary (eg IQ and USA) are acceptable. All terms should be spelt out in full (with the abbreviation in brackets) the first time they are mentioned in the text.
15. Copyright will be with the publisher, BILD. Authors will be obliged to sign a form indicating their acceptance of this.
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